NHS Greater Glasgow & Clyde

NHS BOARD MEETING



Director of Planning and Policy Director of Regional Services 20 December 2016

Paper No: 16/75

# Centre for Integrative Care: move to ambulatory care

# Recommendation:

The Board notes the outcome of the engagement exercise and endorses the proposal to move the services at the Centre for Integrative Care to an ambulatory model.

# **Background and Purpose**

The process to develop the Local Delivery Plan includes detailed scrutiny of the way in which services are provided. The Regional Services Directorate of the Acute Division brought forward for the 2016/17 LDP a proposal to shift the services in the Centre for Integrative Care to a fully ambulatory model. In approving the Local Delivery Plan and subsequently considering public engagement the Board agreed that although this was not a substantial service change we should establish an engagement process to explain the proposed change and ensure that there was clarity that the CIC service as a whole was not under threat. The purpose of this paper is to report back on that engagement and to propose that this service change proceeds.

### Current service

The Centre for Integrative Care currently has seven inpatient beds, which are open from Monday to Friday. The small number of patients admitted to the inpatient beds receive a similar range of therapies to those provided to outpatients. The inpatient service is staffed by nurses there are no other interventions and there is no out of hours medical cover.

The proposal to close the CIC beds reflects the following:-

- Of 6000 CIC attendances 5700 or 95% are outpatients, over 4000 are GG and C residents.
- Around 180 of the 260 inpatients were from NHS Greater Glasgow & Clyde patients, the table below shows the 2015/16 range:-

GGC	181
Lanarkshire	36
Ayrshire & Arran	23
Forth Valley	10
Highland	5
Lothian	4
Others	1
TOTAL	

- Services have already been reshaped in recent years moving from a 15 bed, seven-day unit to 7 beds, open four nights a week. Out of the 6000 patients treated in the service only 260 are admitted.
- There is an impact on the service of the withdrawal of funding and the shift to a named patient only approach by other Boards. NHS Highland, Lothian and Lanarkshire have now restricted access.
- The Centre has been very successful in developing an ambulatory model of care, all services are now available on that basis;
- Arrangements for admissions or overnight accommodation can be made in exceptional circumstances.

### Feedback from engagement

This report includes a detailed report on the engagement process. Feedback from patients and CIC staff highlight a very strong attachment to the inpatient service summarising the points made:-

- Both staff and patients feel that the complex conditions of patients admitted to the inpatient service, along with underlying issues such as anxiety or trauma, benefit greatly from being in a safe and sensitive environment, away from their day to day lives and home environment.
- Many patients experience difficulty sleeping at night, and nurses can work with patients on their sleep problems as and when they arise.
- Staff felt that often patients are dealing with significant trauma or underlying mental health issues and often disclose such issues during the night, when staff can be available to provide a supportive presence.
- Patients feel that significant time with other patients provides the opportunity to interact with people who truly understand what they are going through, assisting with the feelings of isolation that many feel when living with a chronic condition.

In addition to the responses highlighting the perceived importance of the inpatient service a number of other issues and points have been raised. The rest of this section responds to those issues.

Challenge to the ambulatory care model: Our local clinical services strategy and the national clinical strategy describe models of service deliver where inpatient admission is

the exception. The other comparable UK services do not provide inpatient care, there are no CIC beds anywhere else in the UK. A number of patients and CIC staff have expressed the view that the service cannot be delivered on an ambulatory basis. Across our clinical services ambulatory care has become the norm with admission to hospital for planned care being the exception not the rule. In a wide range of specialities there has been a major shift to ambulatory care. This includes the provision of care for complex health problems on an ambulatory basis. The conditions which CIC patients are treated for are similar to patients in mental health, addiction, trauma, rheumatology and specialist pain services. The approach in these services is to support patients to manage their condition in their own environment and overnight hospital admission is not part of the treatment approach.

In-Patient Service at Centre for Integrati Main diagnostic codes for sample of 18	
Chronic Fatigue Syndrome/ME	77
Chronic Pain including Migraines	69
Fibromyalgia	61
Depression/Low Mood	28
Osteo-arthritis/Rheumatoid Arthritis	13
Stress/Anxiety	17
Diabetes Mellitus	11
Post-Traumatic Stress Disorder/Trauma*	8
Cancer	8
Sleep apnoea/Sleep Problems	6
Neuropathic/Functional Neurological Symptoms	6
Multiple Sclerosis	6

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National service: A number of respondents have suggested the CIC should be a national service. Our appraisal is that the service would be unlikely to meet the criteria for national designation. In any event if the service was designated it would still be the responsibility of NHS Greater Glasgow and Clyde to provide the service and we would continue to propose an ambulatory model. We have engaged with Boards who use the service and there is support for the move to ambulatory care.

National pain service: Greater Glasgow and Clyde has been asked to provide the national chronic pain service. The current plan is that this service, which is does not include hospital beds, would be housed in an extension to the CIC. In proposing this change to the CIC we had highlighted that, if the beds were closed, there was potential to accommodate this service within the CIC footprint. The national pain service is provided on an ambulatory basis with patients who require accommodation during the programme being accommodated in non NHS facilities. The reference to this option caused confusion in the engagement process with some patients believing that the CIC changes were driven by the need to accommodate the new service. That is not the case, although an option which does not require the planned new built will save NHS capital costs. It remains our view that this service has strong synergies with the CIC.

**Use of resources:** a number of service changes have been delivered in 2016/17 to make best use of resources and deliver value for money. Shifting the CIC to an ambulatory model reduces costs by approximately £400k.

**Use of the facility:** the new hospital was funded by charitable sources and campaigners have continued to raise the issue whether the Board can use the facilities for other services. In our view this is possible and appropriate with the proviso that any such development should be a service with synergy to the CIC.

### **Conclusion**

This engagement process has enabled us to communicate what is planned, ensuring that the concerns among many patients that the whole service was threatened have been alleviated.

The process has also enabled us to begin to develop thinking about how the CIC might better integrate with other services supporting similar patients. Developing that integration is not a reason not to proceed with this proposed change. The services where there are potential clinical synergies are provided on an ambulatory basis.

We have also been able to hear from patients about what they value about the service and this feedback will enable to shape the redesign of the services to move to ambulatory care. That service redesign would need to achieve a more flexible approach to the delivery of services, with the potential for longer days with built in rest periods and pacing of access to day treatments. In exceptional circumstance if admission is required for acute clinical reasons then that would be into an acute bed through the established routes. If there were major travel issues for a patient distant from Greater Glasgow and Clyde we would arrange non clinical accommodation.

We have been very aware, as this process has engaged with patients and CIC staff that there is a strong attachment to the current model of inpatient care. That can often be the case for patients and staff who are very close to a particular model of care but does not in itself indicate that a proposed change is clinically inappropriate.

The shared view of the Executive and Acute Division teams is that this service can be redesigned to be delivered without beds and that the Board should make a decision to proceed on that basis.

The Board's key Advisory Clinical Committees, Area Clinical Forum, Area Medical Committee, GP and Hospital Sub Committees have confirmed their support for the proposed change.

Author – Ms C Renfrew, Director of Policy and Planning Tel No – 0141 201 4607 Date - 13 December 2016 Informing and Engagement Report December 2016

# 1. <u>Introduction</u>

NHS GGC is considering a proposal to no longer provide inpatient beds at the Centre for Integrative Care (CIC), but to provide all of the current therapies, counselling and treatments on an outpatient or day case basis. The following report describes the engagement process undertaken on this proposal, including the activities to inform and engage with patients and carers on the proposal, and the feedback that has been received during the course of this engagement period.

The period of informing and engaging on this proposal began on the 1<sup>st</sup> September 2016, continuing until 5<sup>th</sup> December 2016, following guidance set out in CEL 4 (2010) from the Scottish Government. A Stakeholder Reference Group was established to oversee this engagement process and the activity undertaken to involve patients and carers in the engagement process.

# 2. <u>Stakeholder Reference Group</u>

The Stakeholder Reference Group (SRG) is a group established to support NHS GGC in how it informs and engages with people on the proposal. During this process, this group offered their perspective on how NHS GGC could inform and engage with patients, carers and other interested stakeholders on the proposal to:-

- Share information;
- Consider how best to inform and engage with people;
- Advise on the development of information and events;
- Utilise knowledge on interested groups or networks;
- Provide feedback on the engagement process;

The membership of the group was designed to involve those with experience of, or an interest in NHS GGC services, and who can provide an objective view on the engagement process and the information provided to patients, carers and other stakeholders. This group were made up of the following members:

- Two representatives from the Friends of the Centre for Integrative Care
- A representative from The Health and Social Care Alliance Scotland (The ALLIANCE)
- A patient representative from the Acute Division Patient Panel
- A patient representative from the Long Term Conditions Managed Clinical Network

Additionally, representatives from the 25% ME Group and the MS Society have been kept on the electronic mailing list to enable them to remain informed on the process. To support these members, this group was also attended by the Director of Regional Services; the General Manager of the Centre for Integrative Care; and the Head of Planning for Regional Services.

This group met 3 times throughout the engagement period. During discussions around the proposal, all members agreed that there was scope for review of the service provided at the CIC. Some felt that a move forward with the proposal could be short-sighted without consideration of the service within the wider context of self management and person centred care policy, however others felt that the proposal to move to an ambulatory model was reasonable and that further service review could take place as part of the redesign that closing the beds would require. The SRG asked that the Board report included detailed material on the patients' views and the patient journey.

# 3. Engagement Activities

This section summarises the engagement activities which were undertaken.

### 3.1 Letters to current patients

Two letters were sent out to current patients of the CIC (2,431 patients). The first letter provided information about the proposal; advised patients where they could get more information; and provided the contact details for a dedicated Patient Experience Public Involvement Manager for any comments, questions or concerns. The second letter provided more information about how patients could make their views known, including an invitation to join the Patient Panel.

# 3.2 Telephone Line

77 patients or carers had individual conversations with the Patient Experience Public Involvement Project Manager via telephone.

# 3.3 Email or postal address

109 individuals made contributions to the engagement process via letters or emails. Correspondence was sent via the Patient Experience, Public Involvement Team; to NHSGGC Public Affairs via MSPs; or directly to the Chairman or Chief Executive. Many people chose to send multiple letters via all of these routes.

Just over half (59) of these contributions were sent by patients of the Centre for Integrative Care. The other contributions can be broken down as follows:

- Family members, carers or friends of patients (6)
- Elected members/ cross party parliamentary groups (11)
- Organisations (2)
- Organised patient group and campaign group for the CIC (2)
- Members of the public, including former employees of the CIC; Integrative Care Clinicians from other areas; GPs both current and retired from NHSGGC as well as NHS Lanarkshire and NHS Lothian (17)
- Current members of the clinical and nursing team at the CIC (13)

### 3.4 Patient Panel

A Patient Panel was established to sit alongside the Stakeholder Reference Group by providing a specific forum for patients and carers of the CIC to:

- Hear and ask questions about the proposed changes to the Centre for Integrative Care
- Think about how best to inform and engage with others on the proposal
- Provide their views on the proposals

All 2,431 patients written to were invited to join the Patient Panel. 28 patients and carers attended the first meeting and 35 attended the second meeting, some of whom had attended the first meeting and others who were attending for the first time. The first meeting focussed on the background to the proposal, and the second on the engagement process and feedback received so far, however both meetings allowed for an open forum for participants to ask questions, give their views on the proposal, and share their personal experience of the Centre for Integrative Care. Reports of both

meetings have been made available to all participants, as well as shared on the dedicated NHSGGC webpage for the proposal. Both reports are attached in Appendix 1.

# 3.5 Drop in Sessions

A Patient Experience Public Involvement Project Manager spent 3 consecutive days in the Centre for Integrative Care between 12pm – 2pm in both October and November to allow patients, carers or any other interested parties to 'drop in' to discuss the proposal.

The drop-in sessions were advertised by:

- sending electronic or paper invites to patients who had asked to be kept on a direct mailing list for information
- on posters displayed within the CIC
- through staff letting people know that the drop-ins were taking place
- on NHSGGC's dedicated website for the proposal.

42 patients and carers used the drop in sessions to ask questions about the proposal; to clarify certain aspects of the proposal and what it would mean for them; and to give their views on the proposal. Many of these people had also shared their views in other ways, e.g. by emailing, calling or attending the dedicated Patient Panel meeting.

Of these 42 people:

- 7 were carers of current or previous patients of the CIC
- 6 had only had experience of outpatient services
- 29 were current inpatients, or had previous personal experience of the inpatient unit.

The drop-in sessions were extremely valuable in allowing in depth conversations with patients and carers about the proposal. Much of the correspondence or conversations with patients reflected some of the wider issues surrounding integrative care or homeopathic care, or focused on elements of care at the CIC which would not be impacted by the proposal. The drop-in sessions were particularly helpful in enabling discussions specifically about the impact of the proposal to remove overnight beds and the benefit that patients recognise from having this service.

### 4. <u>Themes from engagement</u>

The following section provides an overview of feedback received throughout the process.

### 4.1 Inpatient service benefits

#### **Rest periods between classes**

Patients spoke about requiring periods of rest between classes or therapies to allow them to recuperate, recover or to take in properly the information they have been given during classes. The current inpatient model enables patients to go back to their room to have this rest period if required. It also provides some flexibility if patients are too tired to take part in all classes during the day (allows pacing of therapies and treatments).

### Time with other patients

This came across strongly as one of the most important benefits of the inpatient unit. This included:

• Building relationships with other patients who understand what you are going through

- Learning tips on how to manage aspects of your illness/ condition from people who have the same condition
- Helping with the isolation that many people feel in their day to day lives

# Travel and transport

Patients spoke about some of the difficulties that the additional travel would cause if they had to attend on a daily basis. The main issues raised included:

- The effort/ energy it takes to get up in the morning and get to the hospital would disengage some patients. It also means this energy is used up doing this, rather than being kept for the classes.
- Some patients need to be accompanied to the hospital, which would make daily travel difficult.
- Would increase difficulty for patients from further away areas taking part in a daily programme due to the distances travelled (e.g. from parts of Lanarkshire/ Ayrshire).
- Difficulties with public transport/ parking

### Respite

Many patients spoke about the CIC as a place that provides respite from their usual day to day lives. Specifically, this included:

- A break from the normal pressures of their life/ breathing space
- A shift in environment to allow them to fully concentrate on their condition and to absorb what they have learned throughout the day
- Provides a safe space
- One patient mentioned that the inpatient stay sometimes leads to recognition from family or friends about the seriousness of the condition they are living with
- 4 nights as an inpatient at first enables you to engage as an outpatient.

### Support at times of crisis

Patients spoke of the inpatient service as being key in helping them at times when they feel they are at a crisis point. Specifically, patients spoke about:

- the CIC as being a last resort when other conventional treatments failed to help or when they have reached a particularly low point in their illness
- the CIC as a place of hope where they know they can return to if needed
- the majority of patients spoke about the mental health aspects of their physical condition and felt that the CIC specifically provided the emotional and mental help that they needed
- Stopping the 'downward spiral' and enabling them to look at things differently

# Overnight support

Many of the positives that patients described were about the CIC as a whole, and which would not be affected by the proposal, for example, the treatments they get, the staff, or the environment of the hospital. When asked to think specifically about the overnight element, and what made this part in particular valuable, patients spoke about the following:

- The cumulative effect of the treatments and therapies being delivered each day, building on the knowledge gained. Some felt that going on a daily basis would break the continuity.
- The personal/ sensitive nature of some of the illnesses patients have (and some of their underlying causes) takes time to feel comfortable opening up about. The inpatient stay provides this time.
- Patients advised that they have 24 hour assessment or observation when in the inpatient ward helps staff get to know their patients and understand their individual needs.

- Can have access to electro-stimulation and heat lamps.
- Patients also spoke about the emotional support provided by staff during the night if they are upset, need to offload or have trouble sleeping.

# 4.2 Wider service issues

- Cost benefits associated with the CIC as opposed to conventional services available as an alternative to patients.
- View that changes are related to a bias against homeopathic remedies and remove patient choice to use these remedies.
- Patients very much value the service provided by the Centre for Integrative Care and feel strongly about the benefit that they have experienced from their care at the CIC.
- Many have come through various conventional services and do not feel they have had the same level of care, or benefit to their wellbeing.
- Many patients described the CIC as a 'lifeline' to them, and in many cases feel that this has become a place of hope for them when dealing with chronic and complex illnesses.
- Patients feel that this is an exemplary service, which should be used as an example to other services, and indeed expanded rather than reduced.

# 4.3 Engagement Process

There were limited comments received in relation to the actual engagement process undertaken, however it is worth noting the following in terms of feedback that was given by patients and carers.

- Lack of clarity over the role of the Patient Panel after the first meeting.
- Concerns about the chair of the Patient Panel and feeling that an independent chair would have been more appropriate
- The wish for more meetings of the Patient Panel
- Questions about the designation of the proposal as major or minor service change
- Questions about a separate ongoing parliamentary process and how this fits in with this service change proposal.

### 5. <u>Supporting Information</u>

### **Campaign Group**

A campaign group opposing withdrawal or reduction of service at the Centre for Integrative Care has been very active during the engagement. The group submitted an email and supporting documentation against the proposal, which can be found in Appendix 3.

### Staff of the Centre for Integrative Care

13 members of staff submitted written comments on the proposal correspondence in opposition to the proposal. A summary of the submissions are provided in Appendix 3.

### Patient Journey

The Stakeholder Reference Group requested further information on a typical stay in the Centre for Integrative Care, in particular, what happens out with the inpatient programme of classes and therapies. The Senior Charge Nurse and Lead Clinician for the CIC wrote a paper detailing the process of admission to the inpatient ward; describing a patient journey for the 4 night stay on the ward; and describing the classes and therapies patients attend.

This document is attached as Appendix 2.

# Centre for Integrative Care: move to ambulatory care Informing and Engagement Report – Appendices December 2016

# **Appendices Content List**

Appendix 1: Patient Panel Meeting Reports Appendix 2: Inpatient Patient Journey Appendix 3: Submissions Received

- Campaign Team
- Staff summary

# **Appendix 1: Patient Panel Meeting Reports**

### **Centre for Integrative Care Patient Panel**

Report of meeting held on Friday 30<sup>th</sup> September 2016 1.30pm – 3.00pm, Seminar Room, Centre for Integrative Care

### Present:

Catriona Renfrew, Director of Planning and Policy Lorna Gray, Patient Experience, Public Involvement Project Manager

This session was set up to enable patients to contribute their views about our proposed service changes. 2,431 patients were invited to join the panel and 28 patients and carers attended. This report records the issues raised.

#### Overview of proposed service change

The meeting started with an overview of the proposed service change covering the points below:-

### What happens currently?

- The Centre for Integrative Care (CIC) carries out over 6,000 patient episodes each year
- Of this total care treatment delivery, 5% of patients attend for a multiple consecutive day programme of assessment or treatment
- These patients currently have overnight accommodation in the CIC after their treatment each day for the extent of the programme (typically 4 nights)

### What are we proposing?

- Proposing that this 5% of patients return home after their treatment each day as the other 95% of patients do, returning to the CIC for further treatment or assessment the next day
- For patients who have challenges:-
  - Deliver over a longer period than one week
  - giving patients rest between treatment programme days

### What are we NOT changing?

- 95% of our patients attend for either one off appointments or for courses which run over several days or weeks there would be no change for them
- We will continue to provide all of its existing day services in their current setting
- There are **no changes** to these outpatient programmes

This overview also covers some of the facts and figures that were discussed during the meeting and which are detailed below.

### **CIC Current Service Provision**



The table above shows the number of attendances at the CIC in 2015/2016. Of the total of 6,069 CIC attendances:

- 5,737 (95%) are outpatients
- 4,294 (71%) are by GGC residents

# **Current Multi-Day Programme**

- The current programme offers a five consecutive day programme delivered during core hours daily by the nursing team and provides the opportunity to achieve a holistic assessment of patients' needs.
- Patients may also receive Complimentary Therapy or Acupuncture if referred by the Ward Doctor.
- The typical 5-day programme followed by patients is provided below:

Monday	1800	Heartmath Based Practice	
Tuesday	1000	MindfulMovement	
	1115	Spiral of Chronic Health Issues	
	1500	Sleep Hygiene	
	1800	Heartmath Based Practice	
- Wednesday	1000	Mindful Movement/Breathwork	
	1115	Stress Talk	
	1600	Tai Chi / Heartmath Based Practice	
	1800	Nutrition	
Thursday	1000	Mindful Movement/Breathwork	
	1100	Introduction to Exercise	
	1515	Art Therapy	
	1800	23.5 Hour Day Video, Moving Forward /Heartmath	
Friday	1000	Tai Chi / Heartmath Based Practice	

All of these services are available on an outpatient basis

# **Overnight Stay Programme – Activity in 2015/16**

The table below shows the number of episodes of care, and actual patients that have had an overnight stay in the CIC, by Health Board area.

	Episodes	Patients	Share
GGC	224	181	69.7%
Lanarkshire	50	36	13.8%
Ayrshire & Arran	28	23	8.8%
Forth Valley	14	10	3.9%
Highland	7	5	1.9%
Lothian	6	4	1.5%
Others	3	1	0.4%
TOTAL	332	260	100%

The table below shows where the above patients came from by Health and Social Care Partnership locality. The dark blue lines are those localities within the GG&C Health Board area. This shows that the largest number of patients come from the area closest to the hospital.



# **Overnight stay patients by HSCP locality**

# THE 2020 VISION FOR HEALTH AND CARE IN SCOTLAND

'Our vision is that by 2020 everyone is able to live longer healthier lives at home, or in a homely setting. We will have a healthcare system where we have integrated health and social care, a focus on prevention, anticipation and supported selfmanagement. When hospital treatment is required, and cannot be provided in a community setting, day case treatment will be the norm. Whatever the setting, care will be provided to the highest standards of quality and safety, with the person at the centre of all decisions. There will be a focus on ensuring that people get back into their home or community environment as soon as appropriate. with minimal risk of re-admission.'

We must be bold enough to agree and pursue the key actions that will allow us to turn this 2020 Vision into a reality. It is only by doing this that we will secure the health and social care services in Scotland that will best meet the needs of future generations, and demonstrate our ability to deliver a world-leading high quality health and care service to the people of Scotland.

#### The recent history of the CIC An ongoing process of change

- Following the direction laid out in the 2020 Vision (shown above), along with the rest of planned care services across NHSGGC, the CIC has adapted to deliver more care on an outpatient or day case basis
- The CIC has been on a redesign journey for a number of years, guided by the Scottish Government's Long Term Conditions strategy
- As part of this, it has already reduced from 15 inpatient beds, seven days a week, to 7 beds for overnight accommodation four nights a week

### What do other Integrative Care Centres across the UK currently do?

- There are two other large centres in the UK providing NHS Integrative Care services:
  - Royal London Hospital for Integrated Medicine
  - The Portland Centre for Integrative Medicine, Bristol
- In both of these English Centres they have already fully transformed all their services to be delivered as outpatients or day treatment courses and have no inpatient beds

#### **Other NHS GGC Services**

- As well as bringing the CIC service delivery into line with the other UK centres, this change would align the clinical model within CIC to those delivered in other services (e.g. increase in day surgery; increase in outpatient/ day attendances for cancer treatment).
- Treatment programmes for most long-term conditions in GGC are now delivered in an entirely outpatient and day case basis:
  - Dermatology
  - Neurology, inc Multiple Sclerosis, Parkinson's and Movement Disorders
  - Chronic Pain Management Programme

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# Informing and Engaging

• We are delivering an engagement programme with people across the area which will run from September to December 2016

In addition to this overview of the proposal a number of questions were asked about the proposal, and many points were made in response, with patients providing their views and opinions. These questions and points of view are set out in the following section of this report.

### Points made and questions raised

- Why has the proposal has been made?
- The fact that this is the only hospital of its type in Scotland, should that not be a reason for it to be maintained?
- Advised that 5% of patients using the Centre for Integrative Care do so as inpatients and therefore for 95% of patients, nothing would change about their care. There was discussion around this point, with one patient asserting that rather than affecting only 5% of patients, this affected 100% of the patients attending the CIC as they could all be potential patients at some point.
- A comparison was made to other NHS services, stating that although day cases have increased, there is still a need for some beds, as there is always a percentage of people who will need beds. Although just a small percentage needs the CIC beds, they are still needed. Another patient agreed, stating that there would be a need to provide beds and inpatient stays sometimes. The NHS is still expected to have beds.
- What about patients coming from other Boards or the Islands? An ambulatory model wouldn't work for them.
- Ambulatory care is impractical. I think it is too much to ask people to come daily. Secondly, to include other people in Scotland maybe we should be approaching the Government to ask them to make it a National Service and have the funding for it ring fenced.
- Ambulatory care is impractical, you can't expect people to come on a day to day basis, it would not be good for them and could even worsen their health. Being in over-night is part of the treatment, as people need this to recover. I put out a petition this week and what is clear is that people want this service. If anybody wants my email address so they can sign the petition contact me.
- Carer my wife has used this service for a long time and relies on this service. We are from North Lanarkshire. I am disgusted at the decision taken by NHS Lanarkshire to stop referring to this service and I have a meeting with my local MSP about this and I will fight this issue all the way. I think the staff in this place are great and the treatment is wonderful. I will fight against this decision.
- Difficult to talk in front of people and I get rather emotional about this. I struggle to put into words what the inpatient service means to me. This service has been a lifesaver for me. I don't think it has been taken on board the value of this service.
- The Board should be proud of this service. I don't think it will work as an ambulatory service. I think the Board needs to rethink and be proud of the service. The staff treat you well. It has been a lifesaver the treatment I receive here. This is our life line that is being cut. I have chronic conditions and how I have managed to get out of my bed half the time I don't know. I think they should be providing more beds instead of cutting them. Please don't take this service away from us.
- The staff of this service have been nominated for an award. The Board need to

support the staff as they have been under stress as well. The conditions they have been under are ridiculous. You have got to treat your staff good as well.

- Point about more traditional medicines causing side effects. I think you will find maybe everybody in this room including myself have had a really bad time with traditional medicines. Traditional medicines do generally cause side effects and homeopathy does not. Homeopathy heals you and does not mask symptoms. It strengthens your immune system. I think the public in general do not understand that. I think the public need to be made more aware of the benefits of homeopathy. I think homeopathy is the future and not the past and you should not be cutting it down. Another thing I wanted to ask at the beginning some people asked why this is happening now and you mentioned a cut in the budget from Central Government and you are having to decide to cut here or cut other bits of the hospital and you have compared this hospital with other places in the UK and so on. We are aware the NHS has been really run down in England and they have held a campaign all over England to keep basic services going and stop services being privatised. I think we need to move forward and not compare our services with the services down South.
- Inpatient beds provide respite for patients who are also carers if they had to go home after their treatment and continue to care for family members they do not have the time to rest and get the most benefit.
- Patient experienced difficulty getting referral from her doctor initially. Had also felt that she had to hide the treatment she was getting from family members as she felt they wouldn't understand why she was attending. She had a very positive experience and felt that could see improvements in her condition within 2 weeks of attending the CIC. She felt proud that people were coming together to say that they felt this proposal was wrong and felt that it was important that patients from all over Scotland could be afforded the benefits of this hospital.
- One patient from NHS Lothian felt the hospital had been a lifeline. She spoke about a treatment she received and felt that it takes at least overnight to recover there would be no way she could drive home (or be driven home) immediately after the treatment. She also advised that because of the treatment at the CIC, she has been able to reduce the number of pain killers/ other medication that she was taking.
- One patient only attends as an outpatient and felt that the outpatient services had been a lifeline to her, as well as to other patients she has met. She felt that there must have been considerable cost savings on the amount of drugs she would have been prescribed otherwise. This should be taken on board when making this decision. She also mentioned the difference in side-effects compared to conventional medicine. She felt that the service should in fact be returned to a 15 bedded unit.
- Board should look at adding things like acupuncture and complimentary medicine into other health services as there are sometimes the things that people need. It is the small things that the service does that will make peoples life much better.
- One patient apologised for being late, pointing out that due to traffic and problems with parking it took an hour and a half to get to the CIC from the East End of Glasgow. She felt this was an example of the problems that would be experienced with the ambulatory service and therefore needs to be looked at. Felt the service has kept her active and kept her alive. She has however seen reductions in the services offered here (e.g. physiotherapy). The physiotherapy she used to receive 2-3 times a year kept her well throughout the year. Feels this is yet another reduction in service provided.
- Another patient raised the issues of feasibility for patients attending who live outside

the Greater Glasgow area.

- One patient advised they have been attending since it was in the old hospital. He reflected that there was sometimes trouble being referred to this hospital. He felt that there did need to be someone promoting how good this service is.
- One patient mentioned the value of the service as a patient who lives alone, and the care and respite the inpatient beds provide for her.
- One patient suggested that the CIC should remain as an alternative when conventional medicines don't provide a viable solution.
- One patient advised that the Royal Family use homeopathic treatments they are in good health and they felt that all of us are just as important.
- Going back to the 5% of care is carried out as inpatient, there was belief that this would increase if GPs were actively encouraged to support the service.
- CIC provides self-help from the beginning people that use the service are trying to help themselves and keep themselves off long-term medication.
- One patient stated that the meeting was not intended to hear patient testimonies but that is what has happened. They hoped that this will be reported as they felt that the patient voice was omitted in the consultations undertaken in Lothian and Lanarkshire.
- One patient advised they were involved in the above consultations and agreed that they were a 'sham'. They saw this current proposal coming and therefore took a petition to parliament which they are looking at, and have escalated to the Health and Sport Committee. She felt that the entire proposal should be looked at by Parliament. She stated that the hospital was gifted for all patients in Scotland. She has been using the CIC for 22 years and felt that she is only alive today because of the it and that coming here has not only saved £100k but has taken her off the roundabout of services that she was on previously, providing some stability and normality in her life. She felt that investment should be put into the CIC as a model of care and felt that patients and staff should have been spoken to before the proposal made. She spoke about the previous campaign to keep the hospital and stated that she will continue to fight to keep the service as it is.
- Would the Board take the proposal off the table now that it has been escalated to the Health and Sport Committee?
- A patient stated CR should not be involved in this engagement because she had stated in the Scottish Parliament she did not believe in the CIC. CR responded that this was not an accurate account of her contribution to the Parliamentary Committee, she had stated very specifically that she shared the NHS Lanarkshire position (which was being discussed at the Committee) that homeopathy does not have an evidence base. The CIC provides a much wider range of services than homeopathy. The proposal is about the way that we provide these services
- One patient stated that it was not up for debate that most people in the room were on the same side. She felt that it was fairly obvious that this proposal was about money and therefore asked for costs to be provided for:
  - keeping the 7 beds

- increasing the number of beds (back to 15)

- increasing the number of days (7 beds, 7 days a week)

Having this information would then allow the patients to publicise the service and get the information out via the internet and other means, in a positive way.

Responses to specific questions asked

# Why has this proposal been made?

Across all our services, ambulatory models of care are becoming more common. Less and less services are being delivered on an inpatient basis. The Board sees this as a normal evolution of the service, and one that is evolving right across the NHS. Across all services that we deliver we have less and less inpatient beds, and have built new ambulatory care hospitals. Thousands of patients who would have been inpatients years ago are now able to have treatment and return home. We think that model can apply to the CIC. Also there are no other inpatient CIC beds in the UK.

### As the only hospital of its kind in Scotland, should it not be maintained?

We are proposing to maintain the full range of treatments that are offered here. It is only the beds that we are proposing to change. The other two integrated care hospitals in the UK don't have beds and have not had beds for some time. **Even so, surely there is always a need for beds in the NHS?** 

This very much depends on the type of service being provided – the CIC does not provide treatment on a 24/7 basis and so is suited to working as an ambulatory care model.

### Travel for patients coming from other Health Boards

Most of the admissions are from people who live in Greater Glasgow & Clyde. The people that are more likely to be admitted to this service are the ones that live closest to the hospital.

### **CIC** provision as a National Service

The CIC is not currently a National Service and that is not a decision for this Health Board to make. A service can only be designated national if there is support for this from all Health Boards, and other Health Boards have already made their own decisions not to fund this service for their patients. Regardless of decisions by other Boards, or if it was a National Service, our view would still be that it can be delivered as an ambulatory service. Is it financial reasons that are behind the changes?

We have a whole range of financial pressures but our job is to make sure that we identify changes that are about still delivering good clinical care. We need to make changes that don't undermine patients care and I think the concerns here are that this change would undermine patient care. Our view is that moving to ambulatory care for CIC is not just about cuts but more a reasonable measure to deliver care using a different model. So it's not just about cuts.

### **Homeopathy Services**

There are a whole range of opinions amongst doctors about the services provided in CIC, however we are not proposing to withdraw these services for patients. Many doctors don't believe homeopathy has an evidence base but that is not the debate we are having today.

### **Parliamentary Process**

The Board has not been asked by any parliamentary committee to stop this process, and if the Health and Sport Committee want to engage with the Board around this then we would talk to them.

### **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.

CR 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.

# CR 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 awav 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 reprovided. 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 works – 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.

# Appendix 2 – Inpatient Patient Journey

### PATIENT JOURNEY AT NHS CENTRE FOR INTEGRATIVE CARE Clinician Referral to In-Patients at Centre for Integrative Care

Every patient starts their journey in the Out-Patient clinic.

Most of the 'volume' of clinical work and engagement takes place in the various outpatient clinics. This is where a patient first attends after referral from their GP, consultant or other specialist. The In-Patient referral is an important carefully considered clinical decision.

All patients have an initial Integrative Care assessment in the out-patient clinic by either a doctor or the advanced nurse practitioner. This lasts between 80-90 minutes usually. During the course of this therapeutic consultation, it will be decided in partnership with the patient what may be appropriate for that individual, and this is where the decision may be taken to refer for an in-patient 5 day stay. The decision may also be taken at another time when the patient is attending a follow up appointment. Patients continue seeing the same practitioner they saw for the initial consultation, and would return to see this person after the in-patient stay.

On average around 36-42 patients are seen by one clinician each week. Of these, one or two patients may be referred to the in-patient service. Each week on the ward, there may be one or two of each clinician's patients who are admitted. The number of admissions of one clinician's patients, in a year is roughly 60-80. This would be up to 4 % of the total number of patient interactions (clinical out-patients) in the course of a year. However, it is more likely that it is a patient new to the service who would be admitted, so if 6-8 new patients are seen in any given week per clinician, that may be 16-25 % of the new patients seen who may be admitted. (This is just to give a general idea of the pattern).

Since there are only 7 beds available and this is a finite resource (There is enough demand for more beds than are available), the clinicians are mindful of that, so call on other available resources before considering admission. However, with some patients, it is clear in the initial engagement with them in the consultation that they would benefit from an admission.

Some themes that would form part of the clinical decision to refer for admission:

- Would benefit from fuller assessment
- Many complex layers
- Taking them out of their immediate environment would be helpful
- Patient is on downward spiral of chronic ill health and other measures haven't helped
- Willingness to effect change and take on an active role in self care and self management
- Risk of de-compensation in the present situation (not sustainable)
- A need to develop greater self awareness of the problem, which can be facilitated in a compassionate and 'trauma sensitive' environment
- A wish to develop inner strengths and capacities
- Regulation is a problem such as sleep and there is chronic pain or fatigue unresponsive to other input or attempted measures

- Patient is 'bruised and battered' from other encounters with health services and their life experience and needs opportunity to build trust and re-build inner strength and resilience and develop coping strategies
- Person does not have stamina or concentration or emotional strength or capacity to cope with out-patient groups
- Problems such as pain, sleep disturbance and emotional distress, anxiety, low mood and stress would benefit from 24-hour assessment over several days
- The person has not got an effective alternative resource to call on
- There may be a wish to review/reduce medication by the patient or they may be intolerant of everything or have side effects so a non-pharmacological intense approach is needed
- Person is prepared to engage with the experience on offer on the ward (a full explanation of this is given to prepare the patient and ensure this intervention will be timely)
- They would benefit from the creation of better self-care practices from the nurturing and modelling of the clinical, nursing and support staff over the course of the week
- They would benefit from participation in the educational ward programme and compassion-centred care ethos of the ward
- The multi-disciplinary team approach available on the ward will be valuable to this individual
- They are actively struggling, seem vulnerable and 'tune in' to this approach when it is offered
- (Mental health is also assessed to establish whether another referral would be appropriate and that someone's health issues are appropriate for our
- ward environment taking into account the nursing and other resources available and the other patients)

In talking with the patient and in making referrals to the ward clinicians may offer, suggestions for the aims of the admission, although this will be re-assessed by the inpatient team and can be developed as they get to know the patient further during their time on the ward. As these patients have many complex issues, the clinician may choose with their patient a couple of aspects to particularly work on during the admission, such as improving sleep and regulation, or helping with a grief adjustment, or assessing and supporting pain. Other examples include aims to develop self care and compassion which may be particularly relevant for some of the patients who have experienced adverse early life trauma or abuse, where there is self-blame and a difficulty with trust. It may also be suggested looking to develop strategies for self management to help with coping with pain or difficult emotions or responses such as stress or anxiety.

During the week the patient is admitted, the referring clinician will speak with the nurses and doctors involved with their care and also speak with the patient, to get a feel of how they are finding the experience. If the patients are seen at different times during the week, clinicians can often observe a difference or change, but most importantly seeds are sown that they can continue to nurture. It is a personal journey of transformative change for each individual who engages with our service in this way. It is supported yet challenging. This is the future of medicine, where there is an engagement at a deeper level with developing the inner capacities and resources of an individual living with long term illness.

There is also an important follow up of patients in the out-patient clinic usually 2-3 months after their admission, with the practitioner they saw initially, to further assess the value of the work with the patient and reinforce it. Patients themselves say:

"I emerged with fresh hope and courage, a reduction in pain and more knowledge on how to cope"

"For chronically ill people with no other options left"

"Multiple illnesses. Side-effects of medication can be treated at the same time"

"It's the only Ward of its kind in Britain and it enhances LIFE and it gives HOPE!"

"People who need to be taken out of their home environment, to concentrate on finding ways to manage their daily challenges"

"Helping them to live better with their chronic health issues"

We also often hear from patients that they feel able to 'take responsibility for themselves' and also have learnt to 'be kind to themselves' i.e. demonstrating self care and compassion.

A patient I saw yesterday in my clinic that had an admission in June '16:

"I came out feeling fantastic and relaxed, with a lot of things to work on"

"I found it a bit hard to mix, but gradually found I could"

"Sleeping pattern has improved"

"Found the experience on the ward made a difference. Someone listening"

# Five Day Inpatient Experience November 2016

The programme was designed for patients with multiple chronic and/or emotional longterm conditions. Owing to their complex health problems which often include pain, fatigue and poor concentration, this vulnerable group of patients are unable to attend weekly outpatient groups.

The aim of the programme is to promote self-management and give back control to patients through imparting information and supporting knowledge.

The timing of the classes has been based around the daily ward routine taking into account protected mealtimes, patient tea rounds, medicine rounds, 1:1 sessions with nursing staff / ward doctor, and visiting times. Whilst also allowing adequate time for rest between classes and reflection.

Patients are given handouts at the end of each presentation/class and there is also a varied selection of supplementary booklets available for patients to take home.

Relaxation CDs and CD players with headphones are available in the ward.

The seven bedded Inpatient Unit at the NHS Centre for Integrative Care provides individualised, person-centred, holistic care for patients living with a wide range of complex long-term conditions which severely impact on their everyday activities, resulting in devastating changes to their lives and also the lives of their families.

The skilled medical/nursing team deliver a structured self-management programme aimed at providing information and education to enable and empower patients to better understand their condition and to learn about self compassion and self care and to develop coping strategies to improve their wellbeing and quality of life. 'To be the person they want to be'. The nurses are trained to degree level, are highly experienced and have counselling skills.

The ward provides a calm healing space giving patients time away from their home environment and everyday worries to concentrate on themselves, allowing time to reflect and process information from the nurse led classes and take advantage of the invaluable support and encouragement from both medical and nursing staff. 1:1 sessions with nursing staff are available for patients struggling to understand information given, or who have missed classes due to their levels of pain or fatigue.

A team approach towards patient centred care is taken in the ward with medical and nursing staff meeting each morning to discuss each patient in detail and share information in order to work out ways to best support each individual.

An audit is currently underway looking at the effects a 5 day admission to the ward has on a patient's confidence in managing their chronic disease. The following describes one patient's first experience of a five day admission to the ward. Her history, symptoms and experience are typical of many of our inpatients. I will call her Anne.

Anne is a 38 year old lady who was initially referred to the Centre for Integrative Care by her GP. Anne has inflammatory polyarthritis, fibromyalgia and chronic fatigue syndrome. She also has post traumatic stress disorder. She has been prescribed several different medicines to help her pain with limited success and due to debilitating fatigue, she can be virtually housebound sometimes having to use a wheelchair when outside. She can't sleep at night, has become noise sensitive, continuously exhausted and has poor concentration, 'brain fog'. She has no strength in her arms and hands, finds cooking difficult and needs to rest after walking short distances. Anne's husband is ill and can't work and she has two children. She worries about the family and feels guilty she can't look after them as she would like, so feels useless with low mood and low self esteem. If she tries to overdo things, the illness becomes worse and she is in bed for days. "I feel I have lost me". Life is very limited, no social life and no confidence.

# Anne's five day Inpatient experience MONDAY 09:00

- Arrived on the ward exhausted and in pain. Hadn't slept well due to anxiety and fear, unsure what to expect
- Anne and her husband greeted by a nurse and shown to her room
- Nurse explains what Anne can expect to happen throughout her first day and answers any questions
- Anne is given a folder containing the Nurse-Led Self-Management Programme, and this is explained
- Given time to settle in and meet other patients and to rest if this is required.
- In depth nursing assessment and care planning. What are Anne's goals from this admission? Ward orientation
- Lunch followed by Medicine Round and Rest Period
- Anne joined fellow patients at ward dining area. (Staff are aware that patients can initially feel withdrawn and vulnerable mixing with fellow patients, however, nursing staff supervise the mealtimes and are on hand should any problems arise)

By the end of the week, feedback from patients is extremely positive. As they chat with each other they feel less isolated and are meeting people with similar problems and who understand how they feel and the problems they face. Peer group support.

- In depth medical assessment and plan for week. May be given reading material and CD
- Free time whilst medical and nursing staff admit the other patients. Patients can often become emotional following discussions with medical/nursing staff
- Evening meal followed by medicine round, served in ward dining area. All patients are encouraged to join in if possible
- HeartMath based practice (see programme)
- Free time and evening visiting
- Night shift staff on duty and introduce themselves to Anne and discussed the day's events
- Medicine round
- Ward settled for the night

The night nurses are very aware that patients can feel scared and vulnerable in strange surroundings and are on hand to listen to fears or worries which always appear worse during the quiet hours of darkness when patients have little to distract them from their negative thoughts.

# MONDAY 18.00 – 18.30 (approx)

# HEARTMATH BASED PRACTICE

- Meditation based practice to enable patients to connect with inner resource of positive experience to use as a powerful self-healing tool
- Research proven and scientifically based practice shifts heart rhythm from erratic to a more coherent state (Emotional Shift)

### Duration of class allows for an explanation of practice and brief experiential learning.

- Time for discussion if appropriate.
- Structured Practice Posture
  - Breath Heart focus Emotional shift

### Positive benefits to health

- Improved mood
- Lowers blood pressure
- Strengthens immune system
- Restores normal bowel function

### Resources <u>www.heartmath.uk</u>

### MONDAY

Anne was unable to get to sleep - despite being exhausted. She spoke to one of the staff nurses about her family worries and her feelings of helplessness as her family think her illness is "all in her head". She had a 1:1 practice of HeartMath with staff nurse and was given EST (Electrostimulation Therapy) which stimulates acupuncture points without the use of needles to promote relaxation and sleep. This worked quite well for Anne who said she would have used her phone to go on the internet at home.

### TUESDAY 10.00 -10.30 MINDFUL MOVEMENT / BREATHWORK

- 4 X 4 X 4 Breathing
- Introduction of bringing awareness to physical tension stored in the muscles of the body
- Guided instruction from the top of the head down to the feet focusing on releasing tension and promoting relaxation
- Incorporating focus on the breath and breathing with the movements
- Time for Discussion

### Positive benefits to health

- General wellbeing
- Awareness of practice which can improve/assist with pain reduction e.g. back, neck, shoulders.

#### Resources

Mindfulness Based Stress Relief, Jon Kabat - Zinn; Helpguide.org

### TUESDAY 11.15 – 12.00 SPIRAL OF CHRONIC HEALTH ISSUES

### How to understand your body better.

• Ideas on how to help the body function as best as possible.

# **Coping Strategies**

- Boom and Bust
- Low mood

# **Questions /Discussion**

### **Key Principles**

- What does your mind make of this?
- Internal/External Stressors
- Living life to the fullest level possible
- Being kind to yourself

# **Resources**

'Coping with Chronic Fatigue': Trudie Chalder; Living a Healthy Life with Chronic Conditions: Kate Lovig PhD; Physiotherapy: A Psychosocial Approach: Sally French, Julius Sim pg 50-51

# TUESDAY 15.00-15.45 (approx) SLEEP HYGIENE

- Facts about sleep
- Biological Clock
- What disrupts sleep
- Effects on the body due to lack of sleep
- Resetting the body clock
- Daily Structure
- Sustainers / Drainers
- Night-time routine
- Wakefulness during the night

### Resources

PHRD; NHS Public Health Resource Directory

### TUESDAY 18.00 – 18.30 (approx) HEARTMATH BASED PRACTICE – 2<sup>ND</sup> Nurse led practical session

# TUESDAY

Following breakfast and receiving medication, Anne attended all classes as per programme. However during her consultation with her ward doctor, she stated she felt very disconnected and bored, and wanted to go home.

On further discussion with the nursing staff, Anne spoke about issues relating to her post traumatic stress disorder (PTSD) which she felt were resurfacing due to the peaceful ward environment. At home, to keep these thoughts at bay, Anne said she would have used distraction techniques, e.g. computer or TV to help her cope. Following a lengthy talk with the nursing staff, Anne decided to stay for another night but said if her feelings did not change by morning she said she would go home.

Anne again had a 1:1 talk with the night staff, receiving emotional support and practical help with her breathing techniques. Anne also received EST for pain and relaxation.

### WEDNESDAY 10.00 – 10.30 MINDFUL MOVEMENT /BREATHWORK – 2<sup>nd</sup> Nurse led practical session

### WEDNESDAY 11.15 – 12.00 STRESS TALK

- Stress- Fight or Flight
- Effects on body
- Impact of constant or regular stress on body
- Hyperventilation Cycle
- Coping Mechanisms

### Resources

NHS Public Health Resource Directory; Helpguide.org

### WEDNESDAY 16.00-16.45 (approx) TAI CHI / HEARTMATH BASED PRACTICE

Either Tai Chi led by Complimentary Therapist Or 3<sup>rd</sup> Nurse led HeartMath practical session

### WEDNESDAY 18.00 – 18.45 (approx) NUTRITION

- Foundations of Balanced Healthy Living
- Food is Fuel How to make Healthy Choices
- Some facts You Are What You Eat
- What is Food?
- Eat less CRAP Carbonated drinks, Refined sugar, Additives, Processed food
- Eat more FOOD Fruit/veg, Organic proteins, Omega 3 fatty acids, Drink water
- Food Shopping card
- Understanding Fat in the Diet
- Healthy Proteins
- Good Carbs
- Too much Sugar
- Making Choices
- Emotional Hunger Vs Physical Hunger Recognition of Both
- Changing Habits

### Resources

Food Rules, Michael Pollan; Helpguide.org

Throughout the day, our complementary therapist works with each patient in turn, referred by clinicians.

During the evening, the senior charge nurse/charge nurse provides a session of acupuncture treatment to any inpatients that have been referred by ward doctor.

### WEDNESDAY

Anne awoke feeling something had changed. Everything from the classes seemed to make sense. She said she felt relieved, calm and relaxed and began to enjoy her stay, no longer wishing to go home.

She attended all classes as per programme. On further discussion with nursing and medical team, Anne spoke about how she had finally managed to relax deeply using the breathing techniques she had been taught at the classes. This had allowed her to find 'head space' and apply clarity to her life and to see a way forward as before she felt 'lost'. Anne explained to staff that 'she felt as if she had lost her way amongst the illness, pain, fatigue and stress that had consumed her entire being'. Anne said she was now aware of what she can and can't do to help her manage her own illness.

She said she realises making time for herself is important and she needs to structure a routine to incorporate mindful movement and breathing techniques, but also let family members take responsibility for themselves.

Following the Sleep talk, Anne says she realises she needs to stop using her phone and internet during the night if she can't sleep. Most importantly, she said she needs to get out of bed and set up a routine. Her positive state of mind continued with a treatment from the complementary therapist which she found beneficial.

### THURSDAY 10.00 – 10.30 MINDFUL MOVEMENT / BREATHWORK – Nurse led practical session

### THURSDAY 11.20 – 12.00 INTRODUCTION TO EXERCISE

- Introduction to Exercise
- Reducing Sedentary Behaviour
- <u>Outline</u> Chief Medical Officer Guidelines Benefits of being alive Where to start Reducing prolonged sitting time
- Guidelines
- Benefits of moving more, sitting less
- Lifestyle Comparison 1900 2014
- Avoid long periods of sitting
- Make a plan
- Create goals / check your goals
- Top Tips

### Resources

Chief Medical Officer Guidelines

Following lunch, acupuncture treatment from senior charge nurse/charge nurse given to any inpatients referred by ward doctor

### THURSDAY 15.15 – 16.45 (approx) ART THERAPY

Session usually provided by art therapist. Nurse led session if art therapist unavailable

### THURSDAY 18.00 – 18.45 (approx) MOVING FORWARD

Shown '23.5 hour day' YouTube video.
 (9 minute video by Dr Mike Evans). Talks about taking half an hour out of your 24 hour day to increase your exercise activity.

### • Making a SMART Plan

Patients are asked to choose 1 issue from the programme which they feel would be of the most benefit to them. They are given paperwork and instruction on how to make a SMART Plan. <u>Specific</u>, <u>Measureable</u>, <u>Achievable</u>, <u>Reasonable</u>, <u>Time Specific</u>.

• Diary

Patients given a diary to take home with them. They have to fill in changes they would like to make, and how they managed to achieve this.

• HeartMath Based Practice. Nurse led

# THURSDAY

Anne said her stay was further enhanced by continuation of the programme, input from the physioled class on Introduction to Exercise, and the therapeutic sessions with her ward doctor. Anne also had an acupuncture treatment and was pain free until the following morning.

The art therapy in the afternoon provided light relief for Anne and the rest of the patients, who had now formed strong bonds with each other over the course of the week. Anne felt that the time spent together allowed the patients to talk about how isolated their illnesses made them feel, contributing to a lack of self confidence and low self esteem.

Feedback from the art therapist is that patients often benefit from this shared group session, finding a creative outlet to express their past experiences and emotions.

To conclude the programme, the nurses provide patients with the tools to enable them to take forward everything learned throughout the week. Anne found it very helpful to be encouraged to set herself realistic, achievable goals for when she went home.

During a conversation with the night staff on Thursday night, Anne stated that the week had changed things for her more than she could have imagined. She said she felt calm, relaxed and peaceful with more energy, less fatigue and reduced pain levels. She felt in control of her life again and felt better than she had in 20 years. "I am the person I am supposed to be".

### FRIDAY 10.00 – 10.30

### TAI CHI / HEARTMATH BASED PRACTICE

Either Tai Chi led by Complementary Therapist Or Nurse led HeartMath Based Practice Practical Session

### Further 1:1 sessions from Complementary Therapist

### FRIDAY

The patients meet together for a final Tai Chi class or HeartMath practice. Some patients also receive complementary therapy.

The patients then have a final consultation with their ward doctor and a further plan of action and follow up is discussed with them depending on their individual needs.

Many patients develop friendships during the week and keep in touch after discharge, offering each other much needed support and encouragement.

The patients are discharged during the afternoon.

At a subsequent outpatient appointment 3 months later, Anne was still doing well.

She has had some days when her health problems were more problematic, but she said she is now more accepting of her condition and following her admission, has the knowledge and tools to help her cope and manage her symptoms.

She was also delighted to report that she had managed to take her younger daughter on holiday for a few days during the October school holiday.....something she thought she would never be able to do again.

Anne has written about her experience in the ward and asked that I share it with others. Comments from other patients who have experienced a 5 day admission to the ward can be found on the Universal Feedback Cards supplied by NHSGG&C.

### Advantage of overnight beds

Night nurses have the opportunity to identify individual difficulties which may be contributing to the patient's sleep/wake cycle which perpetuates the spiral of ill health.

As research shows, sleep disruption contributes greatly to a person's ill health by causing further depletion of the immune system and disrupted daytime living. Sleep disruption may be due to various reasons, e.g. sleep apnoea, night terrors, ruminating thoughts and pain. Patients may already have a well established pattern of turning night into day and this has serious implications for daytime function causing further anxiety and depression. Immediate measures by staff include EST, heat lamp, administration of valerian and encouragement and support to use relaxation and meditation based practice as taught on the daytime programme. The ward routine and Sleep Talk, attempt to reset the body clock.

Ward staff are skilled and trained in counselling to assist and support patients when they experience difficulties emotionally, when processing information throughout the week. This can often surface at night and support is vital at this time to enable patients to understand their feelings and process them in a positive manner.

Individual 1:1 support is also available for patients who find the supportive environment a safe place to address issues which have affected them for many years.

Staff are there primarily to promote emotional safety for the patient and report to senior colleagues and refer to other specialised services if needed.

The nursing team co-mentor and support each other in working with these complex patients, which helps maintain the sustainability of this service and its innovation and true person centred care. The integration of the ward programme and the measures and support offered overnight contribute greatly to the successful outcomes of a very short, intensive stay in the ward.

Report complied by Senior Charge Nurse C. Fairley, Clinical Lead Dr. J. Mardon. November 2016

### Appendix 3 – Correspondence Received

### Campaign Team

Dear NHS Greater Glasgow & Clyde Health Board,

Can you please include the above documents attached in relation to your current Consultation on the review of services provided at the NHS Centre for Integrative Care and your plans to move it to an ambulatory care model.

The Health Committee document includes speeches that were included in the first ever parliamentary debate on Health to take place in the Scottish Parliament in April 2005 nearing to end when the previous decision was made during the 2004/05 campaign as to whether the Inpatient Integrative Care Unit would close at the Glasgow Homoeopathic Hospital.

As a patient group we would like the submissions made in the Parliament by two patients Isabella Mooney and Catherine Hughes who spoke so as to demonstrate how patient's and their carers depend and rely on the unique and pioneering services that are provided at the NHS Centre of Integrative Care at the former Glasgow Homoeopathic Hospital, to be included as evidence of the importance of care to patient's at the Centre of Integrative Care and the importance of the many and varied holistic treatments it provides.

We have also included papers for your information that were put together in 2004/05 by those working on the campaign team in relation to helping explain the holistic and integrative care model and the care provided at the hospital to demonstrate its effectiveness and its appreciation by the patient's and carers who rely on this care. Patients find the various services provided at the NHS Centre for Integrative Care along with a variety of complementary, holistic and conventional care approaches used to deliver individualised patient centered care.

As a patient and carers campaign team we fully support patient choice and that also includes the availability of holistic and complementary approaches to care to be available on the NHS to patient's who are assessed by fully qualified practitioners, like the staff at the NHS Centre of Integrative Care, who have full conventional medical training with further specialism in a variety of holistic and complementary approaches to care therefore benefiting from the services that they offer. The NHS can benefit greatly from a variety of approaches to care, and as patient's are individuals their care should reflect this.

A number of tools are used by the staff at the NHS Centre of Integrative Care from a wide variety of holistic and complementary approaches available that provides the patient with self management and coping skills to cope with their condition positively and help them to live their life and improve the quality of their life. Patient's who have experienced severe side-effects to conventional medications often derive benefit from the use of other holistic approaches that are not used or prescribed in isolation but as a package of treatment tailored to each patient's individual need following a full and comprehensive holistic assessment. These treatments are cost effective, safe and non-toxic with little or no apparent side effects when compared with those used conventionally and low cost.

It is wrong to suggest that large amounts of money will be saved by the withdrawal of availability of holistic treatments, as the patient's requesting these treatments will still require care and treatment of some description. So should the access to the inpatient beds be withdrawn by NHS GGC then their overall bill and that of other Health Board's is bound to increase as the patient's still require treatment and most conventional allopathic treatment costs a great deal more than that of the holistic treatments and remedies.

If NHS GGC decides to withdraw the availability of access to inpatient beds and the holistic overnight assessment and other nursing and services that are available within the in-patient ward in the Integrative Care Unit in the NHS Centre for Integrative Care then this will only result in a postcode lottery of care as this will adversely affect patients travelling a longer distance from other Health Board areas. This proposal will create an inequality.

As a campaign team we feared that any withdrawal of services from other Health Board's such as NHS Lanarkshire could result in a rebound action by Greater Glasgow and Clyde Health Board given that their Chief Executive Robert Calderwood has stated that should any other Health Board in Scotland withdraw their support or make the decision to stop referring patients from their area to the NHS Centre of Integrative Care at the Glasgow Homoeopathic Hospital then this will cause him to reconsider the future of the Service. The decision of Lothian Health Board and Lanarkshire Health Boards as we feared as had national consequences to all those patient's throughout Scotland who rely on the holistic and integrative care approaches that are so expertly provided by the hospital. It should not be for one individual Health Board to withdraw access to these beds. I would encourage NHS GGC to support the hospital in applying for national funding as at present their are still patients who are being treated from at the NHS CIC by NHS Lanarkshire, NHS Lothian and NHS Highland as well as other Health Boards.

In 2004/05 their was a very successful campaign mounted by patients, carers, staff and supported by a multitude of health professionals and stakeholders and supported by MSPs and decision makers. This concluded and proved that the Centre of Integrative Care was clinically effective and efficient, especially in relation to a patient group that had been failed by other NHS treatments and care. It was also well managed with reportedly very high patient satisfaction rates. The care provided was also cost effective and resulted in other substantial NHS savings in the long term as it helped get patient's off the NHS merri-go-round of costly treatments, interventions and investigations. By teaching patient's self management and coping skills it assisted people to help to live their life more productively.

As a campaign team we are opposed to any reduction in the Service provision and believe that the NHS has much to gain from allowing more patient's with longterm, complex, chronic and degenerative conditions to have wider access to the Services the NHS Centre of Integrative Care both in their local community when it can be delivered effectively and also the ability to be referred to the inpatient unit at the hospital should they require full assessment of their condition and the outpatient department for follow up assessment and a full access to all the services provided in the hospital.

We hope that all members of the Health Board will take an opportunity to visit the NHS Centre of Integrative Care and meet with the patient's, their carer's, the campaign team and staff and also read the collection of patient testimonies in relation to their treatment at the hospital and their experiences of general NHS care by comparison before any further discussions or decisions are made in relation to this type of care model. It is important to fully understand that this care model meets the clinical needs of patients and is truly valued by them and they would oppose any reduction in being able to access the inpatient ward

or any reduction in their holistic care support and access to self-management and chronic disease management courses that are delivered by the hospital which have recently been recognised with awards.

The campaign Team will be happy to try and supply you with any further information should you require this, please do get in touch, we only wish the best for the patient's and their carers and families and am sure that NHS Greater Glasgow & Clyde Health Board if they are provided with all the necessary information, details and facts will come to the same common sense conclusion for the benefit of all the parties and stakeholders involved.

• Provides the best of both worlds ~ Conventional, Complementary treatments & a variety of other individualised therapies that patients feel are beneficial in their holistic care & self-

management that provide emotional, psychological & physical benefits that improve a persons spiritual well-being & improve their quality of life by allowing improved symptom control & better knowledge of the conditions which are often have a co-morbidity & multiple-morbidity and therefore respond better to a holistic approach.

- It is a unique, innovative & pioneering model of care providing holistic & integrated medicine. Providing individualised person centered care teaching self-management skills that help patients to better develop their self resilience & helping to restore a sense of well-being & restore quality of life.
- Fully conventionally trained multi-disiplinary team staff who then specialise in a variety of holistic & complementary approaches. ~ this is the safest way to deliver care for patients with long-term complex conditions too explore holistic & complementary treatments.
- It is a Centre of Excellence that provides the most recent evidence based medicine & approaches through several means of an in-patient unit providing intensive treatment, outpatient clinics & their illness & chronic disease management course The Wel Programme. (www.thewel.org). The specialist medics will decide following a holistic care review which treatments & interventions are clinically indicated in a persons treatment.
- The hospital has several 100% patient satisfaction surveys and continues to achieve extraordinarily high patient satisfaction ratings. This clearly demonstrates that the patients value this model of care & derive great benefit from the care provided within the inpatient and outpatient service.
- Patients attending the unit have generally not been helped or have exhausted all other conventional treatments or they are contraindicated in their care. They value the opportunity to try these holistic & conventional treatments safely through the NHS as patients on the main are on benefits or a limited income due to their condition & could not afford to purchase their care privately. No other services is available providing this complex care pathway providing equivalent care within the NHS or privately and the reason that the NHS CIC achieves such good outcomes and results is particularly due to the inpatient ward which achieves such excellent transformational results and provision of beds elsewhere can provide the same care and will certainly not achieve the same results as a specialist unit that is provided under the same roof with a dedicated specialist team of staff who are providing a unique integrative model of care that is only available within this hospital.
- Accessing care through the hospital is the safest way to receive care as all professionals are initially conventionally trained as if not available in this way this may result in people attending unregulated practitioners who will be charging less but may not have full qualifications. Through the hospital the care is fully regulated & the practitioners are accountable for treatments provided.
- The hospital is located on general hospital campus allowing full access to other medical & surgical specialities if indicated following a full holistic care review & assessment. It also allows access to full NHS medical investigations & procedures. All findings are recorded in patients medical notes giving a more accurate holistic overview to all professionals who access them, this would not be the case if individuals were forced to access private care or be treated within other departments as the care provided could not be the equivalent as to that provided at the NHS CIC.
- Why is the treatment being called into question with such a high patient satisfaction ratings. Given that these patients who have exhausted all other conventional successfully find treatment beneficial within the NHS CIC shows that it works and the Health Board if it invested in this model of care and promoted and expanded access then they would find that it could help more patients and the Health Board and NHS would achieve significant

savings from that of expensive pharmaceuticals and other conventional interventions as the integrative model of care has much to offer patients.

- Inpatient care provided elsewhere will not be the same high quality services as those
  offered in the NHS Centre for Integrative Care which is a Centre of Excellence as the
  hospital provides 'Gold Standard Care' with a specialist trained medical team who deliver
  intensive support & has full medical back up. Outpatient treatment, selfmanagement course and support Groups & charities & other community based services are
  important & have their place but this in addition to the services provided within the inpatient
  unit at the hospital for those patients who require referral to the complex care pathway
  provided at the NHS Centre for Integrative Care.
- The hospital has very high recruitment & retention ratings that means that patients have continuity of care as patients are able to be monitored by the same healthcare professionals (I have had the same named nurse since referral over 22 years ago) who are able to assess patients overtime more accurately if the patient is improving or deteriorating. They are also able to develop a strong professional relationship & build up trust with the patient which helps them to assess their patient through providing a holistic relationship. This same care will not be able to be delivered through an outpatient service or in other locations outwith the NHS Centre for Integrative Care.
- The hospital provides cost-effective care for a cohort of patients that are very difficult to treat due to having extremely complex care needs and the inpatient unit in particular is used by those patients with the most clinical need as referral is only made clinicians if clinical need dictates. The care provided for this cohort of patients with complex care needs is low cost per each patient journey & experience compared to other NHS areas. The funds invested in these referrals however achieve long-term cost saving to the NHS year on year with patients reporting that need to take less medication, that they visit their GP less, have fewer admissions to hospital & less outpatient/ambulatory visits. The patients also achieve improved quality of care & quality of life, this not only adds years to life but puts life in those years. No other current service is providing a similar result so why interfere with a working model that is achieving significant results, as these patients who currently require to use the inpatient i=unit need referral irrespective of where they live and this is best decided by the clinicians working within the NHS Centre for Integrative Care not Health Board management.
- National funding of the hospital & all related satellite out reach services would be a solution to these issues, as this is a true tertiary service. This would allow the hospital it own autonomy for the future investment & development of services that keep evolving in light of the most recent research in chronic disease management and would also stop the postcode lottery allowing equity access to patients throughout Scotland regardless of where people may live allowing portability of care for individuals

There have also been serious issues with the design, question & publicity surrounding this Consultation that have set to confuse people. We believe that the Health Board should also have contacted all the GPs who refer patients currently who may consider this as a referral option (in case they wish referral in future) to this service to inform them about the Consultation so they had an opportunity to participate but this was not carried out. I think it is important that the Health Board to have written to all the stakeholders including those health professionals who use this referral pathway as the reason they refer the patients to the hospital is because they cannot deal with appropriately in the community or within their hospital speciality and trust the clinicians at the NHS Centre for Integrative Care to admit patients to the integrative Care ward. Care provided is in line with Clinical Strategy for Scotland and Realistic Medicine Report by Dr Catherine Calderwood.

# FURTHER RELATED INFORMATION THAT MAY BE USEFUL & INFORMATIVE:

# PATIENT OPINION REVIEWS BY PATIENT ATTENDING NHS CENTRE FOR INTEGRATIVE CARE

https://www.patientopinion.org.uk/opinions?nacs=G507H

# PAPERS FROM 2004/05 Campaign presented to the Board by Catriona Renfrew:

<u>17th May 2005 Minutes of Greater Glasgow NHS Board, Minutes 05/5 Minutes 70-83, Page 4-6 http://www.nhsggc.org.uk/media/213927/GGNHSB(M)05-05.pdf</u>

<u>17th May 2005, Greater Glasgow NHS Board; Board Meeting, Board Paper No 05/41, Future</u> of Homoeopathic Services, North Glasgow Division Review, Attachment 1 <u>http://www.nhsggc.org.uk/media/214300/05-41.pdf</u>

Lecture by Dr David Reilly for the Glasgow Centre of Population Health December 2012 http://www.gcph.co.uk/events/125

<u>NHS Centre of Integrative Care Website created when hospital was built:</u> www.ghh.info NHS Centre of Integrative Care ~ Take a virtual tour & find out more about hospital

www.davidreilly.netDrDavidReilly'sWebsitewww.thewel.orgWebsiteforWelProgrammeChronicDiseaseManagementProgramme

# Health Board Information:

http://www.nhsggc.org.uk/patients-and-visitors/main-hospital-sites/gartnavel-campus/nhs-centrefor-integrative-care/

Information from Dr Bob Leckridge Clinical Director NHS Centre of Integrative Care:

Let's work together <u>http://www.thehealthdoctor.net</u> Celebrating uniqueness - Heroes not Zombies

Here is some very useful information about the NHS Centre of Integrative Care. I do hope that you find it informative and useful along with the attachments. It does however apply back to the 2004/05 campaign to save the in-patient unit to identify the importance of the integrative & holistic model care & directly relates to the in-patient service that was under threat of closure at that time that was eventually reprieved from closure following a 15 month high profile media & political campaign as it was found to deliver improved care outcomes, was cost effective and achieved significant cost savings to the NHS.

Some statistics to back up the improvement in patient quality markers & cost saving delivered to NHS:

### SUMMARY FROM AUDITS OF 200 INPATIENTS AT GHH AT PRESENTATION:

100% had already had conventional care97% has seen a Consultant for the problem85% rated the problem as causing major disruption to daily living67% had previously needed hospitalised for the problem

At a range of 3 -6 months after treatment, (94% response rate):

# **CLINICAL OUTCOME**

70% had a useful improvement in the presenting complaint 67% had a useful improvement in general mood and well being.

### IMPACT ON CONVENTIONAL CARE:

40% reported less consultations with their GP. 36% reported decreased use of conventional medication 33% reported fewer admissions to hospital 30% reported less outpatient/ambulatory visits

Ref: Lewith G. Reilly D. Integrating the Complementary NHS Yearbook 1999 Pages 46-48. Publ. Medical Information. Reproduced from NHS Doctor and Commissioning GP. Summer 98:50-52.

If you require further information then please do get in touch & I will try to answer any queries or questions that you may have.

Yours Faithfully Campaign Team

Campaign Team c/o Library at the Hospital NHS Centre of Integrative Care AT the Glasgow Homoeopathic Hospital Gartnavel Hospital Complex 1053 Great Western Road Glasgow.

Links to supporting documentation from Campaign Team:

Attachment 1: <u>Patient views submitted to Parliamentary Health Committee, 11<sup>th</sup> April 2005</u> Attachment 2: <u>Why there is a need for the integrative care model provided & the patient view why this patient service must be retained</u> Attachment 3: <u>Integrative Care provision at Glasgow Homeopathic Hospital & the importance of this care model to the NHS</u> Attachment 4: Glasgow Homeopathic Hospital Campaign Team – summary of inpatient unit

### Clinical & Nursing Staff at Centre for Integrative Care: summary of views from staff who responded

- Care provided at the centre is truly holistic and patient centred, & is based on a strong & firm medical & nursing base. Puts the patients at the centre of their care, & by developing a therapeutic relationship based on unconditional positive regard.
- Truly unique service for the many, many people who are affected by long term, chronic conditions.
- Increases in the ageing population, obesity, diabetes, chronic fatigue, post traumatic stress disorder and chronic pain means that the need for integrative approaches to care & promotion of self care management will expand & grow.
- Drive to move our service towards an ambulatory care model with a removal of overnight beds is unwise, & counterproductive.
- Providing an environment which is safe, secure and where people can discuss issues is an integral part of the care provided, & often it is at night time that a lot of people with long term conditions have great difficulty with.
- Without beds patients will be too tired to benefit from treatment
- The ward offers a safe 'trauma sensitive' environment and the 5 day stay allows the patients time out from their chaotic lifestyles to concentrate on themselves, understand more about their health problems and also learn how to make changes in their lifestyle to help them self-manage their condition to improve their quality of life.
- The night nurses work with patients on their sleep problems sleep disruption contributes greatly to a person's ill health by causing further depletion of the immune system.
- Night nurses can also utilise electro-stimulation therapy (EST) to help the patient re-establish a healthy sleep pattern.
- Feedback from patients is extremely positive about their 5 day inpatient stay. They say they benefit greatly from meeting others with similar problems, sharing their experiences and learning from each other. They get together in the evenings and discuss the material from the classes. Many friendships are made.
- Admitted patients have multiple health problems and often have traumatic life stories. These patients do not have the necessary energy reserves to be able to travel to our Centre for a few consecutive days without it becoming in fact detrimental to their health.
- These patients need to build a new path with an intensive effort over a few days.
- To break learned behaviour or habits of thinking or daily structure removal from the home environment for a few days away from sick environment is essential.
- The Inpatient ward represents one part of a potential long term strategy to improve the health and wellbeing of Greater Glasgow and Clyde's population. The proposal is a false economy in terms of financial effectiveness.
- The overnight beds allow the creation of a new space outwardly for a few days which is continuous and unbroken and means it is simply easier to create a new space in heads, hearts and general health inwardly which will be harder to be broken when the person gets home at the end of the week.
- Through the process of staying overnight for four consecutive nights it means that the patient can much more easily immerse themselves in the teachings, therapies and ambience of the ward environment and engender a new and hopeful change to start to take shape within, which can be transformative.
- The overnight beds allow patients with chronic health issues of pain and /or fatigue, usually complicated understandably by emotional states of anxiety and depression, time to reflect, acknowledge and accept any lifestyle changes which we discuss/teach during the weekly programme.
- Many patients have trust and possible abuse issues helped by the nurturing ambience of an inpatient stay.
- CIC model of care should be the future of a healthy society.

- Patients who are referred for inpatient admissions have complex conditions and many have horrendous life experiences which manifest in severe chronic pain and fatigue. They do not have the stamina, concentration and emotional strength to attend outpatient groups.
- The interactions that occur in between workshops at the ward both with other patients and with members of the staff can be an important therapeutic element that should not be overlooked and that, again, this would not be achievable during any of the other out-patient programmes we have here at the CIC.
- Closure of inpatient beds, is an abandonment of vulnerable, debilitated individuals who are in more ways than one, victims!
- Patients struggle with physical stamina but they have often become socially isolated and suffer from panic attacks; dissociative states when in stressful situations and can even physically collapse from neurological overload. Often due to childhood trauma night time in particular is a trigger for these dissociative episodes and they really struggle with feeling safe in new environments.
- Nurses promote a relaxed and peaceful atmosphere that is so different from the home environment of the majority of our patients, and this enables the healing process for our PTSD and fatigued patients who are enduring chronic pain.
- In history taking there can be unresolved sensitive issues that require more time and protected space for patients to communicate at their own pace with the qualified inpatient team.
- Patients report that it is the protected space, relaxed environment and supportive, compassionate staff that allows them to feel safe enough to talk about the traumas of the past.
- The current model is clinically effective for the group of complex and vulnerable patients whom it serves, with multi-morbidity and long term conditions. The in-patient programme and experience at the Centre for Integrative Care has been rigorously developed in partnership with our patients and is long established as an important part of the overall pathways of patients within the service. There is a flow and synergy with the rest of the service, which is actively reviewed and sustained, with regular contact between staff in all parts of the service, and the patient always 'held' at the centre.
- The ward is an integral part of the overall work of the service which has won a prestigious National award recently for NHSGCC as Best Resource in Self Management. It has an international reputation, established over many years, and colleagues from overseas come to visit and learn from us.
- The ward is set up to provide a calming, supportive and stable environment, which is Trauma Sensitive and aware, and can offer an opportunity to these individuals for re-regulating.
- The presence of the skilled and supportive staff and the rhythm of the five days' admission enables deep therapeutic work and effect.
- The in-patients offer the environment and opportunity where the development of self care and compassion can be most intensified.