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North Wales Community Health Council

Menopause Services in North Wales

Engagement Events Report

January 2023

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Introduction

This report has been produced by North Wales Community Health Council (NWCHC)

NWCHC is the independent watchdog for NHS services in North Wales and we seek to encourage and enable members of the public to be actively involved in decisions affecting the design, development and delivery of healthcare for their families and local communities.

NWCHC works with the local NHS, as well as inspection and regulatory bodies, to provide the crucial link between those who plan and deliver the National Health Service in North Wales, those who inspect and regulate it, and those who use it.

NWCHC maintains a continuous dialogue with the public through a wide range of community networks, direct contact with patients, families and carers through our enquiries service, complaints advocacy service, visiting and wider engagement activities and through public and patient surveys.

NWCHC represents the "*patient and public voice*" within the geographical area covered by Betsi Cadwaladr University Health Board (BCUHB).



Background Information

In the Spring and Summer of 2022 North Wales CHC (NWCHC) began to receive concerns about availability of HRT medication and also about difficulties experienced generally in accessing care and advice for menopause and peri-menopause issues. This coincided with an increase in public awareness and discussion arising from high profile celebrities speaking openly about their own menopause experiences. At the same time the All-Party Parliamentary Group on Menopause began its inquiry.

North Wales CHC took the decision to apply its Safe Space approach to this issue locally. We undertook a series of events that followed a similar format to the NWCHC 'Safe Space' events in respect of Vascular Services, Mental Health Services and Speech & Language Therapy Services.

NWCHC undertook an extensive publicity campaign, promoting the events through its networks, including the press, social media, schools and colleges, town and community councils, and Local Authorities, care/ nursing and residential homes, school language centres, community groups and organisations, nursery schools and Cylch Meithrin, GP practices, MPs and MS's and Voluntary Services Councils.

Methodology

NWCHC has extensive experience of undertaking public engagement and formal consultation exercises across North Wales. Our experience has enabled us to develop wide-ranging networks across the region and to build upon our resources and tools for undertaking public engagement.

Since March 2020 and in light of COVID-19 restrictions, NWCHC has acquired the technology and skills to undertake virtual meetings.

The NWCHC held four virtual events, with each event focusing on broad themes of Menopause services in North Wales. Additionally NWCHC held two face-to-face events. These events were by invitation only in order to ensure that appropriate social distancing measures could be put in place.

At the start of each session we asked people about their experiences during the pandemic. It is clear that Covid has had a significant impact on service delivery and on patients themselves. In great part this was due to the difficulties in accessing GPs. However, it is clear from our discussions that menopause care and information was not fit for purpose before the pandemic and remains so at this time – not just in North Wales but throughout the UK.

Structure of the Events

All events began with an explanation of the role and function of NWCHC and an outline of the nature and purpose of the events. This included details of the ways in which information shared would be used; the importance of confidentiality within the events; that information would need to be shared in the event that evidence of serious harm or potential criminal wrong-doing came to light.

Discussions were based around the '7 C's';

Compliments, Comments, Concerns and Complaints; Care planning and Care delivery; Communication and engagement.

It was envisaged that some people might not have wanted to be part of any group discussion and might wish to talk on a one-to-one basis. All participants were informed that this could be arranged.

Timetable of Events

Date	Location
20 July 2022	Zoom
03 October 2022	Wrexham
05 October 2022	Zoom
10 October 2022	Zoom
12 October 2022	Connah's Quay
18 October 2022	Zoom

The events were arranged to take place in a number of other locations across the North Wales region. Some of these were cancelled as those who wished to take part preferred to contribute via Zoom, telephone or written communication. Others were cancelled as there was little interest shown in those particular locations.

We soon realised that the timing of the events was crucial. Menopause comes at a time in many women's lives when they have many commitments, in their careers, with teenage children and with ageing parents. We soon found that early evening (*around 7:30 to 8pm*) was best to fit in with busy schedules.

Our report has been shared with the Betsi Cadwaladr University Health Board and we have received the following response:

Fiona Giraud, Director of Midwifery and Women's Services at Betsi Cadwaladr University Health Board said:

"Our thanks go to North Wales Community Health Council for their important work into seeking views about Menopause Services in North Wales. These views, experiences and

feedback are crucial in helping us to understand where improvements can be made and how good practice can be shared.

"We provide specialist menopause clinics at Deeside and Wrexham Maelor Hospital for women across North Wales seeking menopause advice and support. The availability of this service has been communicated to primary care colleagues, supported by clear referral criteria accessible to all GP surgeries.

"Due to rising demand, waits are currently longer than we would like. To inform the further development and expansion of the service, we await the All Wales Menopause Task and Finish Group's report later this month.

"We continue to promote education and awareness on appropriate management of menopause amongst primary care colleagues through regular teaching sessions and intend to build on this approach by introducing webinars.

"With regards to our own workforce, menopause awareness sessions have been held and staff from various disciplines are progressing work on raising awareness of this issue amongst colleagues who can then share this information more widely."

What people told us

"When you have a baby, all the services and support is there. There's nothing like that for the Menopause"

The following case examples are the experiences, as recounted to the NWCHC, of the people who spoke to us during and immediately following our engagement events. Whilst everyone's experience was different depending on personal circumstances, the problems and difficulties they encountered were remarkably similar. Our findings were also consistent with those of the All Party Parliamentary Group on Menopause.

Awareness

"Menopause wasn't talked about in our family, we didn't talk about Menopause, sex or politics"

Almost all of those attending the events told us that "*the change*" was something that had not been discussed openly in their families. As a result, few women were aware of the symptoms beyond hot flushes. Many were unaware that they were in peri-menopause and, for some, the symptoms were distressing and led them to believe that they were suffering a range of conditions such as cancer, early onset dementia or serious mental illness.

"I had physical and mental health symptoms. I expected to have hot flushes and dryness, but I didn't expect it to change my mental health".

Distressingly, some of those seeking help were prescribed anti-depressants, rather than menopause-specific medication. This is against the NICE guidance.

"I had a telephone conversation with my GP and told them the emotional side of it all. I have a feeling of doom, hot flushes, have vivid dreams and wake up feeling as if I've been in a war zone. It's now affecting my life; I feel physically and emotionally exhausted. I told the GP I'm not depressed, I'm Menopausal. The GP prescribed something to help with that, I googled the prescription when I went home, it was Prozac, despite what I'd said to her"

All of our respondents felt that few GPs had sufficient knowledge of menopause and its treatment. They felt that, with a few exceptions, female GPs were little better informed than male GPs. One respondent told us that she was advised against HRT on the basis that it caused cancer.

One woman commented;

"52% of the population in Wales is female. It feels like menopause hasn't been prioritised or seen as important. It's always been a 'taboo' subject, where women of previous generations never talked about it, they just struggled through quietly. I wonder why it isn't seen as a public health condition like diabetes and heart disease?" The North Wales representative of Fair Treatment for the Women of Wales commented that within the Quality and Outcomes Framework (QOF) for GPs; "*it's astonishing that Menopause isn't referred to. It doesn't seem to be on the QOF in England either*".

Most had discovered that that during the pandemic, social media was a better source of information than NHS primary care, allowing them to speak to others going through menopause and share information and experiences. However, the information available on the web is often conflicting and confusing and it can be hard to know who to listen to. This could be something BCUHB could help with.

Fighting for Treatment

All of the women we spoke to told us that they had to fight to get the treatment they were now receiving. Most of them felt that they had to go private to get a diagnosis and informed and effective advice on medication and care.

"I didn't have confidence that the GP would have enough knowledge about it. I paid to be seen privately, to get the right advice. There was a huge cost involved, especially when you have blood tests and scans, it all adds up. I couldn't afford it anymore, so I approached my GP surgery. The GP didn't know about the menopause clinic. The GP said that they couldn't refer me to the menopause clinic as they didn't know anything about it. After pushing for it, I managed to get referred there in the end".

Betsi Cadwaladr has commissioned a specialist menopause clinic. This clinic should deal with the most complex and severe symptoms. However, there is a low level of awareness amongst GPs and those who do know of it have been referring patients who should be treated in a Primary Care setting.

A woman who had attended the clinic told us;

"staff at the menopause clinic said that they felt as though all they were doing was handing out notes for women to take to their GPs regarding treatments".

The All Party Parliamentary Group on Menopause also reported that women felt driven to access private care for menopause and peri-menopause;

"When it comes to treatment, the APPG's central concern is that women face a postcode lottery on whether they can access the right treatment from their GP. While some are fortunate to be able to seek private treatment, this is not the reality for the majority of women. Complementary therapies and alternative treatments such as herbal remedies may be helpful for some, but they cannot treat symptoms the way HRT can, and again, come at cost. Put together, this creates a stark socio-economic divide between those that are able to seek treatment via their own means, and those that are not. It is these women who risk suffering the most, with further knock-on impacts on their working lives and financial situations".

All of those we spoke to who had accessed private care expressed concern for the wellbeing of other women in North Wales who did not have the financial resources to seek private treatment.

Several women suggested that it would be useful if at the age of 40, all women received a letter saying what they could expect to notice, explaining the issues and symptoms and suggest that they make an appointment with their GP for a chat and a health check-up. Local well-women clinics and specialist nurses were also suggested. Some felt that pharmacists might have a bigger role to play.

We spoke to women who had a menopause following a hysterectomy – some of them in their 20's. They told us that they had not been aware that a menopause would follow and, for them, the onset of menopause was immediate and severe. Some found it more difficult to live with than the condition that led to the surgery and felt that adequate preparation for the menopause, before and following surgery, was essential. This should include referral to the Specialist Menopause Clinic.

Primary Care

"I went back to the GP and asked for some information or advice about the Menopause. She printed off some pages from the internet and handed them to me to take home. I went home and wept"

The comments we received would make difficult reading for many GPs. We will be sharing the detail with the LMC. All of those we spoke to agreed that they had received very little support from their own GP. One woman told us;

"...it feels that the patient has to drive and steer everything. I got treatment and tests only because I asked for them. It is all reactive not preventative. Women of a certain age should be called in to see a GP for screening".

Impact

Menopause comes at a time when women may be at the peak of their career with considerable responsibility. It also comes at a time when parents are becoming increasingly dependent on receiving their support. For women with children, they are often in the demanding teenage years.

All women spoke of some of the worst and most debilitating effects of menopause being *"brain fog"*, joint pain and mood control. These are symptoms that often respond to medication such as testosterone gel. Unfortunately this is very difficult to have prescribed in Primary Care. Many women had it prescribed privately but then had difficulty in finding a regular supply due to world shortages or their GP was reluctant to issue a corresponding NHS prescription for a continuing supply.

One respondent told us that she had given up work due to the lack of support in managing her symptoms. Another said her symptoms had left her with zero motivation to do anything, some days she did not want to leave the house or speak to anyone and that the thought of going to work was one that she could just not face – she felt lost.

Some reported that they had struggled with managing symptoms so much that they had given up their jobs or taken a less responsible post.

On a positive note, some workplaces had pro-active menopause policies and a serving police officer told us that her employer, North Wales Police, had been more supportive that the NHS care she had received. They offered yoga, mindfulness and counselling sessions, provided practical help, support and training with men encouraged to attend events.

This approach is to be applauded. The APPG on Menopause highlighted the loss of skilled female workers in all sectors due to poor menopause care;

"CIPD, the professional body for Human Resources and People Development, told the APPG that menopause transition at work strikes at the heart of women's economic participation. Their research showed that 59% of women said menopause has a negative impact on their work, 30% said they had been unable to go into work because of their symptoms, while only a quarter felt able to tell their manager the real reason for their absence. They found that in total, almost a million women in the UK have left jobs as a result of menopausal symptoms. With many at the peak of their careers during the menopause transition, this exacerbates gender inequality in senior roles and adds to the gender pay-gap.".

For sectors with a high proportion of female employees this is particularly relevant. At Betsi Cadwaladr University Health Board, for example, 70% of their employees are female with many in the age range most affected by peri-menopause/menopause. The benefits of providing these key workers with the support they need to cope with their symptoms and stay in work are potentially huge.

The British Menopause Society have set out "ten top tips" in their guide to practitioners and these recommendations align closely with the All Party Group report and the wishes and suggestions of our respondents;

- All women should be able to access advice on how they can optimise their menopause transition and the years beyond. There should be an individualised approach in assessing menopausal women, with particular reference to lifestyle advice, diet modification as well as discussion of the role of HRT.
 - In women aged 45 years and over, the diagnosis of perimenopause or menopause should be considered based on their symptoms alone, without confirmatory blood tests.
 - HRT should be offered as first line treatment for symptoms related to the menopause including vasomotor symptoms and low mood/anxiety after discussing the short-term and longer-term benefits and risks.
- The decision whether to take HRT, dose and duration of its use should be made on an individualised basis after discussing the benefits and risks with each patient. This should be considered in the context of the overall benefits obtained from using HRT including symptom control and improving quality of life as well as considering the bone and cardiovascular benefits associated with HRT use. No arbitrary limits set on age or duration of HRT use.
- Oestrogen alone HRT is associated with little or no change in the risk of breast cancer while combined HRT can be associated with a small increase in risk of breast cancer. However, this risk is low in both medical and statistical terms, and should be taken in the context of the overall benefits obtained from using HRT including improved quality of life as well as the cardiovascular and bone protective effects associated with HRT.
- Transdermal rather than oral HRT should be considered in menopausal women who are at increased risk of VTE, including those with increased BMI.
 - Vaginal oestrogen should be offered to women with urogenital atrophy (including those on systemic HRT) and treatment can be continued for as long as needed to relieve symptoms.
 - If HRT with adequate oestrogen intake has not been effective, testosterone supplementation can be considered in menopausal women with low sexual desire.
 - Women with Premature Ovarian Insufficiency (POI) and early menopause should be advised to continue HRT until at least the age of the natural menopause.
- Referral to (or seeking advice from) a specialist menopause service should be considered where menopause specialist input is required if:
 - Treatments do not improve menopausal symptoms
 - · Ongoing troublesome side effects with treatment
 - . Women who have contraindications to HRT
 - . Where there is uncertainty about the most suitable treatment options for a woman's menopausal symptoms.

Author: Mr Haitham Hamoda in collaboration with the medical advisory council of the British Menopause Society.

NB In 2019 FTWW (Fair Treatment for Women of Wales) published a patient-led report on Menopause which is also consistent with recommendations made in this report and the All-Party Group report. "Making the Case for Better Menopause Services in Wales" is available on the FTWW website (www.ftww.org.uk).

Summary

Our Safe Space reports do not set out recommendations; the comments of service users about their experiences speak for themselves and should form learning points for NHS professionals. Set out below are the key issues;

- Lack of general awareness in the wider population about perimenopause/menopause – our respondents suggest that this is an issue that should be taught at school alongside sex education and health awareness generally. Men, as well as women, need to be included in this. Such education would allow women to prepare for menopause with appropriate lifestyle adjustments – but this can only be done if there is awareness and knowledge of the issues
- The need for Well-Woman Clinics for those women approaching menopause symptoms of brain fog, muscular pain and mental health issues such as depression and anxiety can be prepared for and mitigated. Presently they come as a shock for many women who are expecting just hot flushes. Not all women suffer severe symptoms and many just need support and advice to cope well with the condition
- Paucity of knowledge and experience in Primary Care about diagnosis and treatment
 of menopause
- Within North Wales there is a lack of awareness of the role, and even the existence, of the Specialist Menopause Clinic. We have been informed that it is being used inappropriately
- Knowledge of HRT use appears to be limited and out of date in some Primary Care settings
- Menopause affects all of the female population at some point in their lives and has a knock on effect in the home and the workplace. Yet it is not treated as a public health issue in the same way as, say, diabetes or heart disease.

Acknowledgements

We thank the people who took the time to tell us about their experiences and share their ideas.

We hope they influence Betsi Cadwaladr University Health Board to recognise and value what they do well – and make improvements so that the things that cause very real difficulties for people using the NHS are addressed.

Feedback

We want to hear what you think about this publication, and any suggestions about how we could have improved it, so we can use this to make our future work better.

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Social Media:				
CONTECHTO OT THINALES COM				

Presentation

Menopos	Menopause	
CYNGOR IECHYD CYMUNED Community Health Council Coc gogledd Cymru / North Wales Cic	CYNGOR IECHYD CYMUNED COMMUNITY HEALTH COUNCIL CC GOOLEDD CYMRU / HORTH WALES CHC	
Digwyddiadau Ymgysylltu â'r Cyhoedd	Public Engagement Events	
2022	2022	
NorthWalesCHC NWCHC ONWCHC		
Croeso	Welcome	

- č Diolch i chi gyd am ddod
- č Fy enw i yw Geoff Ryall-Harvey, Prif Swyddog Cyngor Iechyd Cymuned Gogledd Cymru (CICGC). Mae hefyd aelodau o staff ac aelodau gwirfoddol y CICGC yma heddiw
- č Thank you all for attending
- č My name is Geoff Ryall-Harvey, Chief Officer of the North Wales Community Health Council (NWCHC). We also have members of NWCHC staff and volunteers here today

Cyflwyniad

- Control Con
- Contract Rydym yn cynnal cyfres o ddigwyddiadau wyneb yn wyneb ac ar-lein ledled Gogledd Cymru

Introduction

- Chis is a listening and engagement event to ensure the user voice is heard by the Betsi Cadwaladr University Health Board
- We are holding a series of ace to face and online events across North Wales

PWY YDYM NI

- Cyngor lechyd Cymuned Gogledd Cymru
- Corff gwarchod iechyd Gogledd Cymru
- Annibynnol a Chyfrinachol
- Yn cynrychioli Profiadau Cleifion o ddefnyddio'r GIG
- Monitro a Craffu ar Wasanaethau lechyd
- Ymgysylltu â Chleifion
- Gwasanaeth Eiriolaeth
 Cwynion

WHO ARE WE?

- North Wales Community Health Council
- Health watchdog for North Wales
- Independent and Confidential
- Represents the Patients Experiences of NHS
- Monitors and Scrutinises Health Services
- Patient Engagement
- Complaints Advocacy Service

CICGC -Ein Gweledigaeth

- č Bydd CICGC yn gweithio i ddatblygu gwasanaethau iechyd sydd yn cael eu dylanwadu gan farn a chyfanogiad cleifion a chyhoedd Gogledd Cymru
 - č llais cyhoeddus cryf yn adlewyrchu'r hyn sydd gan bobl i'w ddweud am wasanaethau iechyd
 - cysylltu â'r rhai sy'n cynllunio ac yn darparu gwasanaethau iechyd yng Ngogledd Cymru er mwyn sicrhau eu bod yn croesawu ac yn dysgu o'r adborth a roddir

NWCHC – Our Vision

- NWCHC will work to develop health services which are influenced by the views and involvement of the patients and the public of North Wales
 - strong public voice reflecting what people have to say about health services
 - c liaise with those who plan and deliver health services in North Wales in order to ensure that they welcome and learn from the feedback given

Beth <u>nad</u> ydym yma i'w wneud

- Cartafod canmoliaeth, sylwadau, pryderon, cwynion ynghylch gwasanaethau y tu allan i wasanaethau Menopos
- Carafod unrhyw fater arall sy'n gysylltiedig â BIPBC y tu allan i Wasanaethau Menopos

What we are <u>not</u> here to do

- Discuss compliments, comments, concerns, complaints regarding services outside of Menopause Services in North Wales
- C Discuss any other issue associated with BCUHB outside Menopause Services in North Wales

Rheolau Sylfaenol Ground Rules

- Control Parchu barn eraill efallai nad ydych yn cytuno – ond dyna eu barn!
- Cyfrinachedd dim recordio, dim nodiadau mewn urnhyw ffurf am stori rhywun arall heblaw am CICGC
- č Caniatáu i eraill siarad, bydd pawb yn cael cyfle

- Respect other participant's views - you might not agree - but it's their view!
- Confidentiality no recording or note taking in any form regarding anyone else's story except by NWCHC
- Allow others to speak, everyone will get an opportunity

Y Fframwaith

The Framework

- č Bydd yr holl gyfraniadau yn anhysbys, bydd angen i ni gael manylion cyswllt gan y rhai sy'n cymryd rhan – ond ni fyddant yn cael eu rhannu
- č Bydd angen rhannu gwybodaeth pe byddai niwed difrifol neu gamymddwyn troseddol posib yn cael ei ddatgelu
- All contributions will be anonymised, we would need to take contact details from participants

 but these will not be shared
- Information would need to be shared in the event of serious harm or potential criminal wrong doing being disclosed

Y Fframwaith ...parhad

č Bydd CICGC yn cefnogi unigolion os oes angen cymryd pryderon neu awynion ymlaen i BIPBC

The Framework ...continued

the NWCHC will support individuals if concerns or complaints need to be taken forward to BCUHB

Heddiw

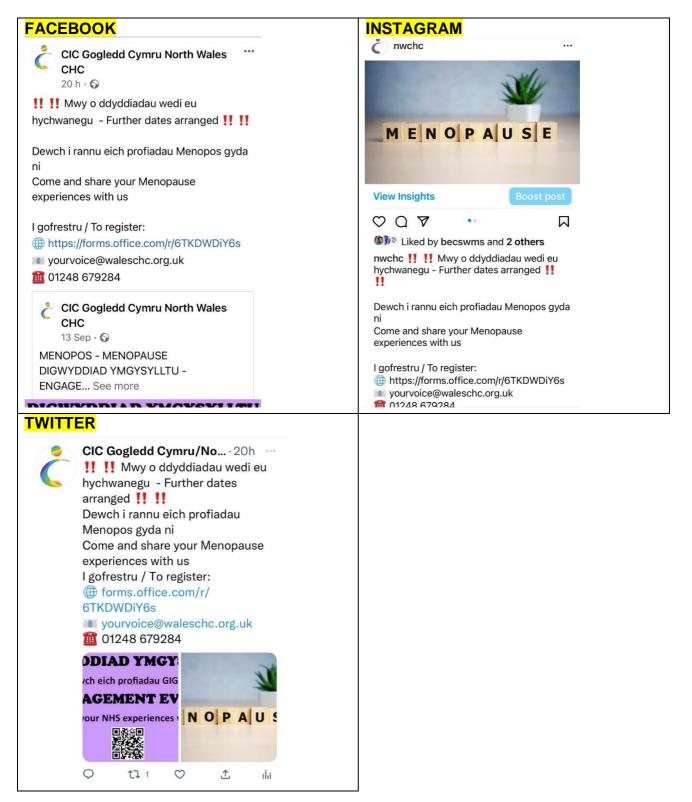
- č Canmoliaeth, **C**omments (sylwadau), **C**oncerns (pryderon) a Chwynion
- **C**hyflawni Gofal
- č Cyfathrebu ac ymaysylltu

Today

- ¿ Compliments, **C**omments, Concerns and **C**omplaints
- č Cynllunio Gofal a č Care Planning and Care delivery
 - ¿ Communication and engagement



Sample of NWCHC Social Media Posts





23 JUNE 2022

MENOPAUSE: HEALTH WATCHDOG TO SEEK VIEWS

The health services watchdog for North Wales – the North Wales Community Health Council (NWCHC) - wants to hear from people about their experiences of Health Services during menopause.

The NWCHC will be hosting a series of events across the region inviting patients, their carers and their families to talk about all aspects of Health Services in North Wales affecting people whilst going through the menopause.

Mr Geoff Ryall-Harvey, Chief Officer for NWCHC said "This is an opportunity for people to have their say. We know that in the build up to (perimenopause) and during the menopause, many may need to access a whole range of different health services and their experiences might vary considerably. It is vital that we are able to present the feedback we receive to those who make decisions and policies about health services in North Wales".

Mr Ryall-Harvey went on to say "We want to hear from as many as possible. Our events will be held across the region and will be structured around a number of aspects about health services such as compliments, concerns and complaints, care planning, care provision and communication. We understand that in some instances, people might wish to share their experiences in a more confidential way and we will ensure that there is an opportunity for such discussions to take place privately. We will be providing people with the opportunity to meet either in person, or remotely over video-conference if they so wish. Further events will be arranged in due course."

The events will scheduled are

Date	Time	Venue
Monday, 27 June	10.00 – 12.00	Zoom meeting
Wednesday, 20 July	13.00 – 15.00	Zoom meeting
Tuesday, 27 September	10.00 – 12.00	Zoom meeting
Monday, 03 October	09.00 – 13.00	Performance Space Ty Pawb Market Street, Wrexham LL13 8BB

Wednesday, 12 October	09.00 - 13.00	Quay Building Fron Road, Connah's Quay, Flintshire CH5 4PJ
Monday, 17 October	13.00 – 15.00	Zoom meeting

Those wishing to attend will need to register in advance by contacting the North Wales Community Health Council on tel: 01248 679284 (*nb there is an answerphone system in operation – please leave a message and a member of our team will be in touch*) or by e-mail yourvoice@wales.nhs.uk

You can also register your attendance by filling in an on-line registration Form by using the following link:

https://forms.office.com/r/6TKDWDiY6s



NB Registration is on a first come, first served basis but we will put on additional sessions as necessary

Note for editors

- North Wales Community Health Council (CHC) is an independent statutory organization which represents the interests of patients and the public in the National Health Service in North Wales. It came into being on 1 April 2010 as part of the reorganization of health services in Wales and covers the counties of Conwy, Denbighshire, Flintshire, Gwynedd, Wrexham and Ynys Môn. The six counties have a combined population of around 675,500.
- The Community Health Council has six local committees, one covering each of the six counties. Each local committee comprises members drawn from three sources: councillors nominated by the relevant local authority, people nominated by the local voluntary sector organizations and local people appointed by Welsh Assembly Government.

Ends

North Wales Community Council - Contact details

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