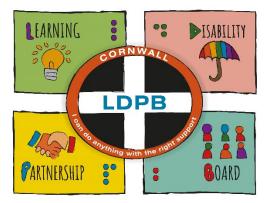
Learning Disability Partnership Board



(Microsoft Teams link: Click here to join the meeting)

30 May 2024	Meeting Date: Thursday 30 May 2024
	Venue: St Erme Community Centre Castle Field Trispen Truro Cornwall TR4 9BD
1:30	Welcome and refreshments 1.30 pm

1



11 12 1 9 3 8 7 6 5 2:00	Please sit down Meeting start time: 2pm
Welcome	Introductions and apologies (2:00-2:15)
	Minutes and actions from the last meeting. Easy Read version – Page 5 Standard version – Page 17 (2:15-2:20)
Updates	Updates from members (2:20-2:40)
	The Aim of Today's Meeting Healthwatch Cornwall, Citizen Checkers and Cornwall Partners in Policymaking (2:40-2:50)

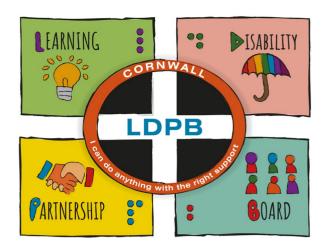
	Break (2:50-3:00)
	Developing the Partnership Board Lived Experience members (3:00-3:55)
	Any Other Business (12:25-12:30)
11 12 1 2 9 3 8 7 6 5 4:00	End of the meeting

Meeting Guidance – Keeping Members Safe

- Everyone has the right to meet in a safe atmosphere.
- All voices have the right to be heard.
- Work in partnership with each other. Listen and respect each other's views.
- Do not single out individual Members. You may disagree with them but do not make personal attacks.
- Do not interrupt. Be guided by the Chair.
- Never share private information about anyone. It is against the law for a professional to share a patient's medical history.
- If a member chooses to share private information about themselves, this must not be shared to other people outside of the meeting.

Healthwatch Cornwall operate a Zero Tolerance policy on Bullying and Harassment.

This applies to both face to face and online meetings.



Learning Disability Partnership Board Meeting



20 February 2024

at Truro Community Library and on Microsoft Teams



Who was there

Name	About them
Mike Hooper (Chair)	Healthwatch Cornwall
Robert O'Leary	Healthwatch Cornwall
Alex Seaman	Self-advocate, Brandon Trust
Amanda Wilton	Patient Council Derriford UHP
Anthony Dunn	Self-advocate, Citizen Checkers
Charlotte Day	Cornwall Partnership NHS Foundation Trust
Charlotte Polglase	Citizen Checkers
Chris Ballett	Mencap
Dina Holder	The Women's Centre Cornwall
Ebony Rose Thomas	Self-advocate, Citizen Checkers
Fliss Hedge	Cornwall People First
Francesca	Self-advocate, The CHAMPs
Imogen Groves	Self-advocate
Jenna Pulley	Cornwall Partners in Policymaking
Julie Pape	Self-advocate, The CHAMPs
Karen Gregory	Mid-Cornwall Hub
Karen Hooper	Cornwall Council
Karl Potts	Cornwall Partnership NHS Foundation Trust
Kate Spenceley	Citizen Checkers

Name	About them
Laura Keeper	Blantyre Day Services / Cornwall People First
Lewis Henry	Self-advocate, Brandon Trust
Lizzie Dennison	Cornwall Council
Lucy Lawler	Cornwall Partnership NHS Foundation Trust
Marie Lobb	Self-advocate, Healthwatch Cornwall
Megan Julian	Cornwall Partnership NHS Foundation Trust
Nadia Myers	NHS Integrated Care Board
Rachel Mellor	Brandon Trust
Rachel Pearce	Cornwall Council
Sam Burridge	Cornwall Council
Sam Edwards	Cornwall Partnership NHS Foundation Trust
Sandra Ward	Parent Carers Cornwall
Steve Hillman	Healthy Cornwall
Vicki Allan	Cornwall Council
Wayne Williams	Self-advocate, Mid-Cornwall Hub

Who could not make it

Name	About them	
Councillor Jane Kirkham	Cornwall Council	
Alison Short	The Advocacy People	
Christopher Jordan	Self-advocate, Parish Councillor and book keeper, Cornwall People First	
David Burns	Self-advocate, Citizen Checkers and Healthwatch Cornwall	
Sgt Flo Linscott	Devon and Cornwall Police	
Jane Rees	Cornwall Hospitals NHS Trust	
Jo Cope	Jobcentre Plus	
Jo Pike	Cornwall Partnership NHS Foundation Trust	
Kevin Beveridge	Cornwall Council	
Marie Martin	Self-advocate	
Neil Carpenter	Advocate, Cornwall People First	
Paula Volkner	NHS Cornwall and Isles of Scilly Integrated Care Board	
Professor Rohit Shankar	Cornwall Partnership NHS Foundation Trust	
Rosi Van Dam	Cornwall Partnership NHS Foundation Trust	
Sam Maddern	Cornwall Partnership NHS Foundation Trust	
Sam Mokkoram	The Advocacy People	
Steve Dymond	Self-advocate, Healthwatch Cornwall	
Dr Victoria Parnell	Cornwall Partnership NHS Foundation Trust	
Zoe Rawlence	Specialist Parenting Service	

What we talked about



Everybody agreed that the minutes of the last meeting were correct.

Updates from members



Sandra Ward said that lots of parent carers were going to their coffee mornings.

A drop-in event will be held at the Eden Project on 7th March 2024.



There will be lots of information for parents, carers, adults with learning disabilities and/or autism and young people with Special Educational Needs (SEN).



It is Eating Disorder Awareness Week.

Sandra Ward told the Board about local work on ARFID -Avoidant/Restrictive Food Intake Disorder



There is a new group called the Local Policy Advisory Group.

They want people with Down Syndrome to tell them what should be in the government Act.

It was being led by the Cornwall Down's Syndrome Support Group.

The first meeting is on:

lst March at 1pm at Camborne Rugby Club.



CORNWAI

Down's Syndrome

Support Group

Wayne Williams said that it is very important for people to get the right support.

Boards like this one are very important. They make sure that people are heard



Dina Holder told the Board about the work of **The Women's Centre Cornwall** and **The Divas**.

They are training lots of organisations across Cornwall and Devon.



The Divas are often sharing the lead and the feedback is very positive.

Domestic abuse or violence affects many people with learning disabilities and autistic people.

The Divas are teaching staff about the needs of those people.



The Women's Centre and **Cornwall People First** will be working together in 2024.

The work will be about healthy relationships for both men and women.



Anthony Dunn said that there are lots of self-advocates on the Board that know how to deliver training.

The Board needs to make use of these experts.



Anthony also told everyone that it is very important to have your Annual Health Check.



Julie Pape said The CHAMPs had worked with the Screening Liaison Nurses.

The screening liaison nurses support people with learning disabilities to be checked for illnesses.

They have made a song together to get more people screened.

It is a cover of Beat It by Michael Jackson.



Fliss Hedge from Cornwall People First has been working with Cornwall Council.

They have talked to people with learning disabilities about housing and support.

<u>To see an easy read presentation</u> <u>click here.</u>



Fliss said that the Practice Partners Project is going well too.

They had started Access All Areas groups.



Amanda Wilton is on the Derriford Hospital Patient Council.

Recent work found out that the hospital needs to do more to let patients and carers know about these things:

- Oliver McGowan training
- Hospital Communication boxes
- The Hospital Passport app

Good news is that most rooms have quiet areas and accessible toilets and showers.



Amanda Wilton said that 290 staff at Derriford will have Oliver McGowan training from March.

More training will happen in August.





Christopher Burns got in touch with Healthwatch Cornwall about the Job Centre and the DWP.

He is worried about poverty and people not getting support to get a job.

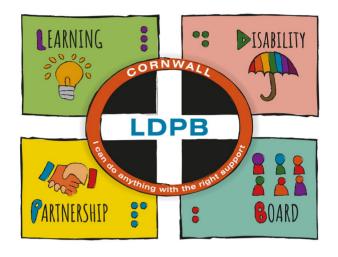
His words and artwork made it all the way up to the Government.

But the letter they sent back was too long and full of jargon.

The Board agreed that the DWP Working Group needed to start up again.

Mike and Robert will do that.

Partnership Board – Planning for the year ahead



The Partnership Boards team have been working with the Citizen Checkers and Cornwall Partners in Policymaking.

They want it to be led by people with learning disabilities.

You need to be able to tell us what we need to hear about your lives.



Self-advocates have told us how the meeting should be run.

We have listened. The next meeting will be set up how you want it to be.

You will tell us what we should talk about over the next year.



Service providers all agreed to help as many people to join as possible.

Let's make the Partnership Board a fun place to be.

And let's get things done.

Next meeting:





St Erme Community Centre





MEETING NOTES:	Meeting of the Learning Disability Partnership Board
DATE:	Thursday, 29 February 2024
LOCATION:	Truro Community Library and on Microsoft Teams

ATTENDANCE

Name	Position	Organisation	
Mike Hooper (MH) (stand-in Chair)	Partnership Boards Officer	Healthwatch Cornwall	
Robert O'Leary (RO)	Partnership Boards Lived Experience Project Officer	Healthwatch Cornwall	
Alex Seaman (AS)	Self-Advocate	Brandon Trust	
Amanda Wilton (AW)	Parent carer of a young adult with profound and multiple LD	Patient Council Derriford UHP	
Anthony Dunn (A)	Peer Advocate and Lived Experience Lead	Citizen Checkers	
Charlotte Day (CD)	Speech and Language Therapist, Learning Disability Team	Cornwall Partnership NHS Foundation Trust	
Charlotte Polglase (CP)	Co-Facilitator	Citizen Checkers	
Chris Ballett (CB)	Community Partner, Our Active Community - St. Austell and Clay Country & Project Manager - All Move	Mencap	
Dina Holder (DH)	Community Engagement Manager / Divas Facilitator	The Women's Centre Cornwall	
Ebony Rose Thomas (ERT)	Self-Advocate	Citizen Checkers	
Fliss Hedge (FH)	Operational Lead	Cornwall People First	
Francesca (F)	Self-Advocate	The CHAMPs	
Imogen Groves (IG)	Self-Advocate		
Jenna Pulley (JP)		Cornwall Partners in Policymaking	
Julie Pape (JP)	Self-Advocate	The CHAMPs / Healthy Cornwall	
Karen Gregory (KG)	Service Director	Mid-Cornwall Hub	
Karen Hooper (KH)	Karen Hooper (KH)Interim Head of Commissioning for Learning Disability, Autism and Mental HealthCornwall Council		





Name	Position	Organisation	
Karl Potts (KP)	Assistant Psychologist, Specialist Parenting Service	Cornwall Partnership NHS Foundation Trust	
Kate Spenceley (KS)		Citizen Checkers	
Laura Keeper (LK)	Self-advocate, service user (BDS) and Trustee (CPF)	Blantyre Day Services & Cornwall People First	
Lewis Henry (LH)	Self-advocate	Brandon Trust	
Lizzie Dennison (LD)	Proper Job	Cornwall Council	
Lucy Lawler (LL)	Student Nurse, Learning Disability Team	Cornwall Partnership NHS Foundation Trust	
Marie Lobb (ML)	Self-Advocate and Community Promotor	Healthwatch Cornwall	
Megan Julian (MJ)	Screening Liaison Nurse	Cornwall Partnership NHS Foundation Trust	
Nadia Myers (NM)	Student Nurse, Learning Disability Team	NHS Integrated Care Board	
Rachel Mellor (RM)		Brandon Trust	
Rachel Pearce (RP)	Assistant Commissioning Officer	Cornwall Council	
Sam Burridge (SB)	Commissioning Officer	Cornwall Council	
Sam Edwards (SE)	Consultant Adult Learning Disability Team	Cornwall Partnership NHS Foundation Trust	
Sandra Ward (SW)	Parent carer of a young adult with profound and multiple intellectual disabilities, Director of Parent Carers Cornwall and Chair of Carers Partnership Board	Parent Carers Cornwall	
Steve Hillman (SH)	Health Improvement Practitioner, High Risk Groups Adults	Healthy Cornwall	
Vicki Allan (VA)	Strategic Commissioning Lead for Learning Disability and Autism, Working Age Adults Services	Cornwall Council	
Wayne Williams (WW)	Self-Advocate	Mid-Cornwall Hub	





APOLOGIES

Name	Position	Organisation	
Councillor Jane Kirkham	Learning Disability Partnership Board Chair	Cornwall Council	
Alison Short	Advocacy Coordinator	The Advocacy People	
Christopher Jordan	Self-advocate and Volunteer book keeper (CPF) and Parish Councillor	Cornwall People First	
David Burns	Self-advocate and Community Promoter	Citizen Checkers and Healthwatch Cornwall	
Sgt Flo Linscott	Diverse Communities Team Lead (Cornwall)	Devon and Cornwall Police	
Jane Rees	Manager Learning Disability and Autism Team	Cornwall Hospitals NHS Trust	
Jo Cope	Disability Employer Advisor	Jobcentre Plus	
Jo Pike	Screening Liaison Nurse, Primary Care Liaison Team	Cornwall Partnership NHS Foundation Trust	
Kevin Beveridge	Area Director, Adult Social Care	Cornwall Council	
Marie Martin	Self -advocate		
Neil Carpenter	Advocate	Cornwall People First	
Paula Volkner	Transforming Care Project Coordinator	NHS Cornwall and Isles of Scilly Integrated Care Board	
Professor Rohit Shankar		Cornwall Partnership NHS Foundation Trust	
Rosi Van Dam	Clinical Lead: Mental Health Liaison Practitioner	Cornwall Partnership NHS Foundation Trust	
Sam Maddern	Lead liaison and Screening Nurse, Community Adult Learning Disability Team	Cornwall Partnership NHS Foundation Trust	
Sam Mokkoram		The Advocacy People	
Steve Dymond	Self-advocate and Community Promoter	Healthwatch Cornwall	
Dr Victoria Parnell	Clinical Lead, Specialist Parenting Service	Cornwall Partnership NHS Foundation Trust	
Zoe Rawlence	Specialist Nurse	Specialist Parenting Service	



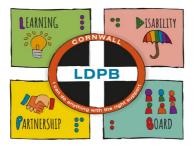


ACTIONS AGREED AT MEETINGS

Action	Responsible	Status
Agree format of May meeting	PB Team / JP / KS	Actioned.
Reconvene DWP working group.	PB Team	Not started.
Learning Disability Strategy	VA	Updates and involvement as appropriate
Share details of Cornwall Council vacancies for people with learning disabilities.	KH / PB Team	Ongoing. To be shared with the Board as vacancies go live.
Update on opening the Safe Places Scheme to neurodiverse individuals.	FL / SM	Updates as the work develops.
Updates on Accessibility Advisory Group for RCHT as appropriate.	MH	Updates will be shared as received.
LeDeR report updates.	SS	Updates will be shared as received.

Item	What was discussed	Action
1.	Welcome, introductions and apologies	
	MH welcomed everyone and advised that the meeting was being recorded for minute taking purposes. Permission would be sought from individuals if it was to be shared beyond the meeting.	
	MH ensured that everyone understood the meeting etiquette and how to contribute to the meeting if they had joined online.	
	MH invited everyone present to introduce themselves.	
	Apologies received were relayed as detailed above.	
2.	Minutes of and actions from the meeting held on 30 November 2023	
	The minutes of the previous meeting were confirmed as a true record.	
	MH ran through the actions as recorded within the minutes of the last meeting, detailed above.	





Updates from members	
Parent Carers Cornwall	
SW reported that coffee mornings for parent carers continued to be well attended and would continue into the Spring.	
A drop-in information event would be held at the Eden Project on 7th March 2024. There would be lots of information for parents, carers, adults with learning disabilities and/or autism and young people with Special Educational Needs (SEN). LK said she would be interested in attending and SW said that she would liaise with her outside of the meeting.	
It was currently Eating Awareness Week and there had been a good article on the BBC about Avoidant/Restrictive Food Intake Disorder (ARFID). It was understood that there was a Health focus on ARFID in Cornwall it was hoped that the Board would be updated accordingly at future meetings.	
MH had circulated information about a new Local Policy Advisory Group for adults in Cornwall with Down Syndrome. The first meeting would be held on 14 th March, venue to be confirmed.	
The Hearing Families film screening had been held the week before. It was a very hard-hitting film but necessary to help to make sure that everyone in Cornwall with additional needs is treated fairly and receives the best possible care. JP said that the film had been created with Cornwall Partners in Policymaking and it was hoped that it would be the start of an ongoing campaign.	
RO asked if the film could be shared with the wider community yet. JP said that the ICB had given agreement to share but there was no date yet.	
The Women's Centre Cornwall / Diva's	
DH reported that the Diva's had been delivering a lot of training lately, firstly for organisations that work with people with learning disabilities to be able to identify individuals that may have	





experienced forms of abuse. Great feedback had been received, including one manager that said that they had been educated on the barriers facing people with learning disabilities in accessing support. Hearing from the Diva's direct had been very impactful.

Staff from domestic abuse and sexual violence services were trained in how to better understand and support people with learning disabilities. Again, feedback had been excellent, particularly from the role play element that was based upon reallife lived experiences. It was hoped that it could be rolled out across Cornwall.

Another positive outcome was that the Psychology Team within the Adult Learning Disability Service were now having regular meetings with the Diva's to consider how to develop services. The first focus would be understanding trauma. Links were also being built with the Specialist Parenting Service.

In March there would be training for Victim Support and First Light.

A key focus moving forward would be the rollout of healthy relationships training for groups within the community. DH asked that anyone with any advice, contacts or offers please make contact.

Wayne Williams

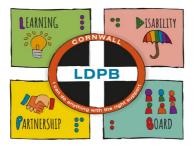
WW stressed the importance of people receiving the support that they need. He had recently watched a television programme that had demonstrated the negative consequences when people did not. Giving people a way to have their voices heard, like this Board, was very important.

Anthony Dunn

AD emphasised the high level of training that self-advocates in the room had undertaken and their experience in delivering training. There are also many other experts by experience within the county. This Boards needs to make use of all of that expertise.

AD also stressed the need for people with learning disabilities to





have an annual health check and the key role that GP's have in promoting them. SH said that Healthy Cornwall had been trying to work with GP's to improve uptake for a long time. MH suggested that could be an area of focus for the Board, should it agree to it.

The CHAMPs

JP reported that the team had been working with the Screening Liaison Nurses to record a song to encourage uptake. A cover of 'Beat It', by Michael Jackson.

They had also designed new training focusing on diabetes.

SH promoted a current vacancy within the team for a Health Improvement Practitioner and Safe Places Coordinator.

Cornwall People First

FH reported on a project called 'Count me In' that was being undertaken with Cornwall Intellectual Disability Equitable Research (CIDER), a partnership between the University of Plymouth and Cornwall Partnership NHS Foundation Trust.

The research was around involving people with learning disabilities and autism in commercial research, with a view to developing a toolkit for drugs companies to utilise for future lived experience involvement.

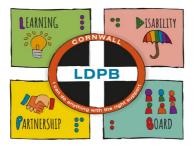
The Practice Partners project was developing well. Access All Areas groups had started and had been supported by the LD Team from CFT.

Work in partnership with The Women's Centre Cornwall to look at issues affecting men, including education around consent, was being developed.

Amanda Wilton

Around 1/3 of the patients using Derriford Hospital in Plymouth were residents of Cornwall. AW reported that she had attended the Derriford Users Group, at which it was reported that members had





undertaken a mystery shop. Of those spoken to, findings included: • Only 3 out of 10 people knew about Oliver McGowan training. • 5 out of 10 people knew about their Hospital Communication boxes. 9 out of 10 knew about Hospital Passports but none knew that there was an app available. • Most rooms had quiet areas for patients and had accessible toilets and showers. Tier 2 Oliver McGowan training was progressing from 5 March. It would be a whole day, face to face, with self-advocates/experts by experience. 290 places had been filled for the sessions and more dates in August would be released. Easy read menus were being produced. The preferred form had been selected by self-advocates. **Healthwatch Cornwall** MH had previously circulated artwork produced by Christopher Burns, a self-advocate member of the Board. One of the issues raised through his art was around poverty and the barriers to people achieving employment. The DWP, who are represented on both this Board and the Autism Partnership Board, progressed the issues raised and a response had been received from Naomi Agius, Acting Head of the Ministerial Correspondence Team. MH shared the letter on screen. It covered two and a half pages, was not in an accessible format, lacked empathy and failed to even acknowledge Christopher. MH said that the response needed to considered with the

MH said that the response needed to considered with the background that the Partnership Boards had managed a working group through 2022 and 2023 with the aim of encouraging the DWP to hear and act upon the views of people with learning disabilities and/or autism with regard to the accessibility of its services and communications. There was consensus within the room that the response was unacceptable.

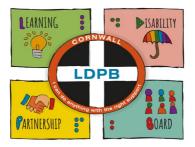
It was proposed and agreed that the working group be reconvened, originally with the previous membership invited but





with a view to widening it out to other members with lived	Reconvene DWP
experience, if necessary.	working group.
RO shared an update from Steve Dymond, self-advocate and Partnership Boards Community Promotor. A new support group had started in Bude for parents of children with autism, ADHD and Special Educational Needs. Attendance from people in the Bude area was encouraged.	
Another group recently formed was 'The Bee Team'. Its aim was to develop bids for funding and it had already proven successful.	
Successful recent events had included a ten pin bowling night and accessible discos for Christmas and Valentine's Day.	
However, a common theme coming from parents was that they felt unsupported by local services.	
MH had circulated Steve's update to the Board, including a list of upcoming events, via email.	
RO updated members that the name of the Older Persons Partnership Board was to change. Feedback from attendees and through wider community engagement indicated that the term 'older person' was off-putting for some and could be perceived negatively. There were two popular suggestions for a new name – Positive Ageing Cornwall and the Ageing Well Partnership Board, with the latter proving to be the winner.	
RO emphasised that the Board was for anyone aged 55 and over but there was also an emphasis on proactively approaching the issues that come with ageing so people below that age could play key roles. No one was excluded so lived experience members of this Board would be welcomed.	
The key focus for upcoming meetings would be developing the approach to and structure of meetings to best engage and encourage participation.	
DH agreed that there was a very large older population in Cornwall with a wide variety of health and social care gaps that need to be	





addressed. Making the Board engaging was very important and it
was exciting to see it taking shape.
ERT expressed the need for services to encourage attendance from people with lived experience. RO agreed and said that issue had been raised following the disappointment of a previous meeting where services were requested to bring lived experience with them but only two of the nineteen services represented did so.
4 Housing and Support Solutions Project
FH reported that Cornwall Council was in the process of recommissioning housing and support services. Having established their key lines of enquiry, they had identified the Reach Standards as the framework that best fits their requirements for qualitative engagement. As part of their stakeholder consultation, they asked Cornwall People First (CPF) to provide opportunities for people with learning disabilities and autism (LD/A) who either use those services or may use them in the future, to talk about their experiences and aspirations with a view to informing the planning process. CPF talked to people across the county. Some lived independently, others with family or in supported living settings. Some had formal support, others did not. CPF's goal was to capture a snapshot of
'ordinary lives' (Practical Guide to Reach Standard, p21) in Cornwall in 2023.
An easy read presentation is on the Healthwatch Cornwall website - <u>Click here</u> .
To read the detailed report - <u>Click here</u>
5 Update from Cornwall Partnership NHS Trust
Professor Rohit Shankar had requested that he provide an update to the Board on current developments within the Integrated Care Board that could impact upon ground level services.
Unfortunately, Professor Shankar had been unable to attend so the





	item was not considered.	
6	Break	
	The Board had a 10 minute comfort break.	
7	Partnership Board – Planning for the Year Ahead	
	Note: Wifi problems were experienced at this point in the meeting which restricted the participation of those that had joined the meeting on Microsoft Teams.	
	The Partnership Boards team had recently liaised with Cornwall Partners in Policymaking to consider how to make the Board as welcoming and as engaging as possible whilst still ensuring that its core remit is met, including co-producing health and care policies and strategies, review the development and impacts of service developments and co-producing and scrutinising the implementation of Cornwall's Learning Disability Strategy.	
	AS suggested that the wifi connection could be poor due to the extreme adverse weather. He added that it showed that everyone being in a room together was preferable.	
	AS continued, saying that the meeting format was not ideal as it was sometimes hard to keep people's concentration levels up when not everyone had time to speak. KS asked how it would be if there were smaller groups sat around individual tables. AS that would be better as everyone would have the chance to speak. Around a big table, people ended up talking over one another and that meant that no-one could understand what was being said. Around a smaller table everyone would get their chance to speak. WW agreed and people around the table clapped. AD said that this was how the Board should work, people with lived experience saying how it should be done.	
	JP said that the key thing will be making sure that the meeting is fun. MH said that he hoped that lots of people with lived experience would be able to join the meeting. Providers around the table all agreed and undertook to promote attendance and to bring along as many people as possible.	PB Team /





	It was agreed that small groups around tables was an approach that people wanted to try out. Various people offered to help by managing a table. AS said that he was happy to do anything required to help out at the meeting.	Cornwall Partners in Policymaking and Citizen Checkers work together to design the
	The meeting would be held at St Erth Community Centre at 2pm on 30 th May 2024. Whilst there would always be an option to join online via Teams, members urged as many people as possible to attend in person. WW emphasised how it was better when people met face to face.	meeting format.
	MH closed the item by saying that the Partnership Boards team would assist with transport and costs and encouraged people to get in touch at <u>partnershipboards@healthwatchcornwall.co.uk</u> or on 07880782636 (Mike) or 07384252667 (Robert).	
8	Any other business	
	No further business was raised.	
	MH apologised for the poor wifi connection within the meeting room for the second half of the meeting.	
	The meeting was closed and all members thanked for their attendance.	