

<b>MEETING</b>	Healthwatch Cornwall Steering Group
<b>DATE</b>	March 31, 2015, 10am - 1pm
<b>LOCATION</b>	Fraddon Village Hall

## 1. ATTENDANCE

**Chair:** Jeremy Preedy

**Chief Executive:** Debbie Pritchard

**HC Partners:** Nicki Sweeney (Health and Wellbeing Service, CRCC), Jeanette Toy (Carers service), Debbie Iles (Disability Cornwall), Emma Williams (Age UK Cornwall), Suzanne Leggett (Cornwall People First)

**Board Members:** Margaret Abban, John Evers

**Steering Group Members:** Shirley Polmouter, Geraldine Taylor, June Hackett, Graham Taylor,

**Operational Staff:** James Buist, Josie Purcell, Charlotte Gamble, Jody Wilson, Maisie Parkin

**Apologies received:** Eileen Rix (HC), Charlotte Gamble (HC), Josie Purcell (HC), Ellie Wright (Young People Cornwall)

## 2. ITEMS COVERED

- Apologies, review of minutes and matters arising
- Update on work - CAP, Carers Wellbeing, Parkinson's, Spinal Cord Injury, Neurology, Pharmacies, Children and Cancer Services
- Publications, responses requested and future work, including external research
- Update on Care at Home
- Feedback from partners
- Rate and Review demo
- Discussion about next meeting - guest speaker, training or workshop
- Any other business



## 3. DECISIONS MADE

Item	What discussed?	Action
1	<p><b><u>Update on work</u></b></p> <p>Healthwatch Cornwall (HC) are carrying out small pieces of focussed work in addition to the main research projects.</p> <p><b>Post diagnostic support for High-functioning Autism</b> A Task Group meeting was arranged following feedback from an outreach session - It was identified that there is a lack of support or services for adults who have been diagnosed later on in life with High-functioning Autism or Asperger syndrome by Outlook SW, post diagnosis.</p> <p>The meeting in March was attended by Cornwall Foundation Trust (CFT), Outlook SW and commissioners at NHS Kernow. Representatives from the voluntary sector were invited but did not attend. We were assured that Volunteer Cornwall was coordinating the services available from the voluntary sector in collaboration with Outlook SW. Reporting on this activity will be through CAP Core, which we attend.</p> <p>Other issues raised at the meeting:</p> <ul style="list-style-type: none"> <li>• People discharged from mental health services are not followed up and have to be reintroduced into services</li> <li>• Forensic - people who commit criminal offences as a result of their disabilities would benefit from a follow up service</li> </ul> <p>Multi-agency partners involved in the task group are to identify what services should be provided and map current services and a paper will be written by Sam Wilson, NHS Kernow to be presented to commissioners. Sam Wilson would like the project to be jointly commissioned by health and social care. Martha Warrener, Cornwall Council is interested in including the project under the Prevention agenda.</p> <p>Shirley Polmounter (SP) fed in that it would be useful for the Steering Group (SG) to be aware of the smaller pieces of work that HC are involved in as SG members may be able to contribute due to their personal experiences. Ops team is committed to feeding back to SG any significant activity and would encourage members to join task groups if applicable.</p> <p><b>Carers Wellbeing</b> As agreed at a previous SG meeting, a task group was set up to look at what voluntary carers perceive as important to keep them well and prevent them from becoming the cared for. The group was well attended and it was agreed that feedback is needed and a questionnaire was devised. Representatives have</p>	



<p>agreed to circulate the questionnaire and obtain 10-20 pieces of information. John Evers (JE) raised the issue of the wellbeing of paid carers. This issue will be covered in the Care at Home research.</p> <p><b>Parkinson's UK</b> A survey by Parkinson's UK has identified issues around poor practice particularly around diagnosis, poor communication and follow-up treatment. HC have circulated the report. It was taken to the Quality Surveillance Group (QSG) and this led on to Liz Trew from RCHT forwarding the report to RCHT's Patient Experience Group (PEG). Further research on this topic may be needed as it is a shallow dive report - questionnaires sent out to 500 people with a response from 30 people. It may be an issue to be addressed and resolved internally by RCHT. There was discussion around community hospitals and GPs playing a key role and around the need for Parkinson's awareness and training. HC will keep the issue under observation to see how RCHT progress with the issue.</p> <p><b>Spinal Cord Injury</b> Debbie Pritchard (DP) wrote a paper following feedback from a number of patients with spinal cord injuries who have received poor treatment during emergency transport and admissions and patient transport. The paper was circulated to Peninsular Community Health (PCH) and RCHT and HC are in the process of meeting with the parties concerned.</p> <p>PCH have awareness around incontinence issues and therapy. The feedback highlighted issues with hospital treatment and lack of awareness or knowledge about how people with spinal cord injuries need to be treated, how they may have limited capabilities, when intervention is needed and how their condition can deteriorate rapidly.</p> <p>June Hackett (JH) fed in that there is a lack of holistic treatment at hospitals and focus is on the current health issue without consideration for long term or on-going conditions. JH offered to help with this piece of work.</p> <p><b>Neurology</b> This work is at a very early stage. Particular issue that HC are aware of are around changes to accessing physiotherapy treatment. Jeremy Preedy (JPR) fed in that he is a former member of CANDO (Cornwall Association of Neurological Domain Organisations).</p> <p><b>Pharmacies</b> James Buist (JB) informed the SG meeting that Debbie Priest (DPR) is a HC volunteer who has a background in pharmacy and research and is leading a research project based on issues identified from feedback received. DPR has looked at the</p>	<p>Ops team to keep watch on RCHT progress on this issue.</p>
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	<p>Pharmaceutical Needs Assessment and has raised queries about some possible inaccuracies and is awaiting a response. DPR has devised a draft questionnaire based on issues identified to collect feedback from people using community pharmacies.</p> <p>Margaret Abban (MA) fed in that there has been a query raised about patient ability to access a named brand of medication rather than a generic brand if it suits them better. MA has spoken with Georgina Praed from Kernow CCG (KCCG) about a need for a countywide structured study day with expert input, led by HC so that it is independent.</p> <p>SP gave feedback about how she has experienced no issues with Boots pharmacy in St Austell but when she uses the smaller local pharmacy, there have been several errors. MA has requested the feedback from SP so that she can raise it at the Prescribing Committee.</p> <p><b>Children and Cancer</b></p> <p>As part of Cancer Awareness month at Cornwall College, a post-graduate student undertaking a block placement with Young People First carried out research with 100 people aged between 16-18 years old regarding issues around cancer awareness and education about services. The student has started a draft report and will meet with JB to discuss the report. Graham Taylor raised a question about awareness of young people under 16 and over 18 and there was discussion about further research leading on from the report. JB fed in that the media plays a large role in current awareness of cancer. JPR suggested that due to lack of capacity, HC could approach Peninsular School of Medicine about this and other research topics that students could cover in their dissertations. It was agreed that it was a good idea as long as HC have capacity to oversee any research project undertaken.</p> <p>JPR observed that these were small pieces of work carried out by the operational team without being brought to the SG as HC sometimes have to respond to feedback, and that this was exactly what should be happening, as long as the SG was informed afterwards. DP fed in that there is a Decisions-making procedure which covers short focussed work and if the work develops into a bigger project, it would be discussed with the SG. SP suggested that SG members be informed of any task groups being set up as part of short focussed work, as there may be members who have useful information or input. Short focussed work would not usually involve a task group.</p>	<p>Group to convene to discuss study day after feedback has been collected from Pharmacy survey.</p> <p>SP to report feedback to HC.</p>
	<p><b><u>Publications, responses requested and future work</u></b></p>	



2	<p>There are three project reports which have either been or are about to be published on the new website which went live on March 25:</p> <p><b>End of Life report</b> This report has been discussed at previous SG meetings and is on the new website. Issues highlighted are communication about end of life and support for people who want to live their last days of life at home. HC are collecting additional case studies and following recommendations in the report for multi-agency working, HC will be writing to agencies for a formal response in the next couple of weeks.</p> <p><b>Personal Budgets report</b> The amended Disability Cornwall report is now published on the new website. HC will be requesting a formal response from Cornwall Council about performance measures for personal budgets application process, as the report shows extreme variations in time taken from applications to being awarded and receiving personal budgets. HC are aware that the personal budgets process has been managed by the Shared Services team but from April, it will be managed by Education, Health and Social Care (EHSC) so the release of the report has been timely along with a response requested by the new team managing the personal budgets process.</p> <p><b>Urgent Care report</b> The final draft report has been sent to the panel and once finalised will be published and HC will request a response from relevant parties.</p> <p><b>Possible commission of external research projects</b> Due to an underspend in this year's budget, HC may commission some external projects. HC have a number of source comments on the Continuing Health Care (CHC) assessment and re-assessment process, with particular issues around:</p> <ul style="list-style-type: none"> <li>• CHC processes not being applied</li> <li>• Families and advocates not being contacted to go through the checklist or Decision Support Tool</li> <li>• Applicants appealing the decision when the application is unsuccessful or only part funding awarded to then be awarded full CHC funding</li> <li>• Families having to pay top up fees which HC think may be illegal</li> </ul> <p>Jeanette Toy (JT) fed in that CHC is an on-going issue raised by the Carers Partnership Board (CPB).</p> <p>Another issue identified is about personal budgets including:</p> <ul style="list-style-type: none"> <li>• Confusion about what personal budgets should be spent on</li> </ul>	
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3	<p><b><u>Update on Care at Home</u></b></p> <p>The interim report was sent as a courtesy to NHS Kernow and Cornwall Council for comments before publication. The response by the commissioners led to the report not being published. Jim McKenna has set up a bi-weekly framework meeting attended by representatives for Lot 1 and 2 providers, non-framework providers, Cornwall Partners in Care and council officers to address the issues about care at home. The results of the report were flagged at the meeting. Care Quality Commission (CQC) requested and have received the report, as several care providers raised concerns about the quality of care they would provide within the framework. The report was also</p>	



	<p>sent to Overview and Scrutiny Committee. Cornwall Council have been asked to respond to HC's recommendations in the report.</p> <p>HC and the task group have agreed that the report is unbalanced as the quantity of feedback from paid carers and the cared for is not representative, with the majority of feedback from providers. To address this, HC will collect more feedback from paid carers and the cared for as part of focussed work and will request feedback from providers who do not attend the framework meeting. HC plan to publish the final report in May.</p> <p>It was agreed that in future, HC will ensure that we prepare balanced evidence before publishing it, but that we must protect our independent standpoint.</p> <p>DP fed back that Cornwall Council have responded by working to improve systems and processes to support the framework such as resolving issues with the electronic monitoring system, training, recruitment and the possible offset of costs to put systems in place. Cornwall Council appear not to be addressing the wider issues. DP informed the SG that she has separate meetings arranged with Anna Mankee-Williams, Liz Nicholls and Trudy Corsellis and is hoping to arrange a meeting with all parties.</p>	<p>SG to consider a protocol around interim and final reports.</p>
4	<p><b><u>Feedback from partners</u></b></p> <p><b>Disability Cornwall - Debbie Iles (DI)</b></p> <ul style="list-style-type: none"> <li>• In the last couple of months, Disability Cornwall have doubled in size so focus has been on education and training. Debbie Iles has emphasised the importance of HC to new staff and encourages staff to promote HC in their new roles.</li> <li>• Lots of leaflets been distributed to various groups to promote HC</li> <li>• Special Educational Needs and Disabilities Information, Advice and Support Service (SENDIASS) work with parents throughout Cornwall who may be difficult to engage. DI is hoping to capture information from this group</li> <li>• DI is involved in the Carers Wellbeing task group and is distributing the questionnaire.</li> <li>• Work on Personal Budgets and Personal Health Budgets is on-going.</li> </ul> <p><b>Cornwall People First - Suzanne Leggett (SL)</b></p> <ul style="list-style-type: none"> <li>• SL gave a brief introduction about CPF - a user led self-advocacy charity for people with learning disabilities</li> <li>• CPF run forums across the county. SL has been promoting HC at forums, conducting 1-1 interviews and</li> </ul>	



	<p>sending out questionnaires</p> <ul style="list-style-type: none"> <li>• There was a focus group in Saltash which looked at experiences with dentists and ambulance staff</li> <li>• Issues raised by people include - not knowing how to complain or compliment; lack of psychological support for issues such as bereavement, adoption and termination of pregnancies; personal budgets; and emergency and hospital services</li> <li>• CPF are one of the partners for the new Victim Care service starting in April</li> <li>• SL is also involved in checking the quality of social work assessments</li> <li>• CPF took part in the recent Cornwall Foundation Trust/HC event in St Ives</li> <li>• CPF have a number of events coming up including Blue Light Day which HC will also be attending</li> </ul> <p><b>Health and Wellbeing - Nicki Sweeney (NS)</b></p> <ul style="list-style-type: none"> <li>• No plans to hold any more forums as poorly attended</li> <li>• Been focussing on meeting with groups such as carers, mental health self-help and memory cafes and promoting HC, giving out Have Your Say forms - good response so far</li> <li>• The more “meatier” feedback has come from Facebook - some service users have set up a Facebook group called Mental Health Have Your Say which NS is a part of</li> <li>• The Facebook group collectively are not happy with mental health services and in particular, the out of hours service. They have formed an online forum and a campaign which will have coverage from Radio 2, Radio 5 and Radio Cornwall</li> <li>• There appears to be confusion about who can access the out of hours service - service users under the Home Treatment Team are prioritised and CMHT service users are able to access the service</li> <li>• Another issue is with the single point of access self-referral process not being widely publicised and often, once triaged being told to go back to the GP.</li> </ul> <p>There was discussion about gaps in service. NHS Kernow is aware of issues and DP reported that Cornwall Foundation Trust (CFT) are keen to address individual cases. There were comments about CFT’s disinterest and indifference, particularly in the case of recent joint engagement events with HC which have been poorly publicised; venues have been largely inaccessible with minimal footfall. Geraldine Taylor (GT) fed in that she attends a CFT group, Whole Life which looks at a holistic strategy. The group are planning an event in June inviting service providers to look at and give feedback on the strategy and an event on October 9 to launch the strategy, as Mental Health day is on Saturday October 10. There were</p>	
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	<p>comments that service users are reluctant to engage partly due to their mental health conditions, but also as historically their voice has not been heard and improvements to services have not been implemented. It was agreed that HC will get involved in these events.</p> <p>The discussion also considered whether the commissioning of Mental Health Services by the KCCG was sufficiently comprehensive or tuned to the needs of the community and this may be an issue that HC may need to explore in future.</p> <p><b>Carers Service - Jeanette Toy (JT)</b></p> <ul style="list-style-type: none"> <li>• JT is involved in both the Carers Wellbeing and the Care at Home task groups</li> <li>• Carers Service are involved in forums - attendance was down last quarter, although attendance was slightly up at the last forum</li> <li>• JT is also involved in the Response to the Care Act - Part two. Copies been sent to DP and JB. JPR has requested a copy. JT will be sending it to the SG</li> </ul> <p><b>Age UK Cornwall - Emma Williams (EW)</b></p> <ul style="list-style-type: none"> <li>• EW has been working with Eileen Rix (HC) at Age UK daycentres - good responses gathered, some positive</li> <li>• EW is involved in the Carers Wellbeing task group and is sending out questionnaires</li> <li>• Changes to the advocacy contract starting in April. The existing service will go to Citizens Advice Bureau. Age UK Cornwall have a new advocacy contract focussing on the new Care Act</li> <li>• CEO Tracey is on a 3-6 month secondment with NHS Kernow, Acting CEO is Nigel</li> <li>• Maintenance Cognitive Stimulation Therapy funding has ended so therapy is no longer being offered. However, as volunteers are trained the therapy may be offered if the venue is free. DP suggested accessing mental health grants; EW will speak to NS about it.</li> </ul>	<p>JT to send copy of Response to the Care Act - Part two to JT and the SG</p>
5	<p><b><u>Rate and Review demo</u></b></p> <p>As Josie Purcell was unable to attend the meeting, JB briefly spoke about the new website. The website design is the same as taken up by Healthwatch Torbay, Healthwatch Plymouth and Healthwatch Devon.</p> <p>Functions:</p> <ul style="list-style-type: none"> <li>• Lists all publicly funded health and social care services in Cornwall</li> <li>• Rate and review tool - star rate a service and leave</li> </ul>	



	<p>feedback. Feedback is monitored before being published</p> <ul style="list-style-type: none"> <li>• Have Your Say is still accessible on the website</li> </ul> <p>The SG were encouraged to use the Rate and Review tool and to promote it. Currently, service providers are unable to respond to comments and feedback. This issue is being addressed and from April this function will be available to service providers.</p> <p>JE fed in that he found navigation difficult when he tried to find reports. It was agreed that a half day information session about the website and collection of feedback will be organised in April or May.</p>	JW and JB to arrange website information session
6	<p><b><u>Discussion about next meeting</u></b></p> <p>It was agreed that guest speakers and summary feedback from HC partners will form the next meeting. As discussed earlier, Nicky Oxley will be invited to give information about CCQC. The SG would also like to invite Laura from Cornwall Council to talk about the new Care Act.</p>	HC to invite guest speakers to next meeting re: CCQC and the new Care Act
7	<p><b><u>Any other business</u></b></p> <p><b>Patient Reference Group</b> JPR has been invited by NHS Kernow to be part of a small group of patients and representatives to be informed confidentially about intentions and plans and asked to comment on drafts before publication. JPR asked whether there would be a possible conflict of interest. After discussion, it was agreed that it would be appropriate for JPR to be involved as a representative of HC. JPR will speak with the Chair of the group about HC involvement.</p> <p><b>Cornwall Care Quality Collaborative (CCQC)</b> CCQC has been set up by NHS Kernow and is a collaboration of managers from nursing homes, Treliske, community hospitals, South West Ambulance Service Trust (SWAST) and private care providers to identify best practice and identify training needs in order to achieve best practice. There are five work streams including prevention and treatment of pressure sores, medication control, admission and discharge and education and training.</p> <p>CCQC will look at the NHS complaints database to identify issues and where improvements to services need to be made. CCQC has approached HC to request sharing feedback information. There was discussion about whether this would be appropriate. It was agreed that it was a good opportunity if HC could share general topics and not individual cases and remain independent. The SG will invite Nicky Oxley, Clinical Governance Lead, KCCG to the next meeting to discuss it further before a decision is made.</p>	JPR to speak with the Chair of the Patient Reference Group about HC involvement



	<p>JW attended the CCQC launch in place of JPR as he was unable to attend and JPR attended the last meeting. There was discussion about whether a Board member could represent HC if CCQC becomes a strategic group.</p> <p><b>Liaison with complaints agencies</b> JE asked for an update. DP fed back that complaints is a national issue - Healthwatch England are currently doing work on complaints; Local Complaints Network are looking at complaints in the county; and CQC are also addressing complaints. HC are waiting to see what happens with the Local Complaints Network. There was a brief discussion about complaints, whistleblowing and good practice and a request for a focussed meeting.</p> <p><b>Patient Experience Group</b> JE attended this group with JB. JE has been invited to participate in point of care observations in clinical settings.</p> <p>SL raised the issue about provision and access for people with communication difficulties, as CPF come across these issues on a regular basis. JB fed in that Cornwall Council are intending to map organisations and keeping the information up to date</p> <p><b>ASIST Suicide Safer Cornwall Course</b> GET fed back that she attended a free two day course which is available in various locations. GET recommended the course.</p> <p><b>Kings Fund - Local Healthwatch: progress and promise</b> King's Fund carried out a review of around six local Healthwatches and the report has been published. Copies were handed out to the SG.</p>	<p>HC to invite Nicky Oxley, KCCG to speak at the next meeting</p>
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<b>NEXT MEETING</b>	Healthwatch Cornwall Steering Group
<b>DATE</b>	May 19, 2015 , 10am - 1pm
<b>LOCATION</b>	Office 2, Victoria, Station Approach, St Austell, PL26 8LG

