

MEETING NOTES:	Carers Partnership Board
DATE:	November 06, 2018 - 13:30pm - 15:30pm
LOCATION:	Wesley Halls, Wesley Road, Redruth

ATTENDANCE

Name	Position	Organisation
Sandra Ward (SW)	Carer and Chair	Parent Carers Cornwall
Nuala Kiely (NK)	Partnership Boards Officer	Healthwatch Cornwall
Sophie Smith	Data Officer	Healthwatch Cornwall
Barbara Ellenbroek (BE)	Councillor - Redruth	Cornwall Council
Andy Fox (AF)	Chief Social Worker	Cornwall PFT
Kelvin Yates (KY)	Manager	Kernow Carer's Service
Kevin Downing (KD)	Service Coordinator	Action for Children
Mark Griffiths (MG)	Head of Patient Experience	Derriford hospital
Claire Martin (CM)	Deputy Chief Nurse	RCH
Stuart Cohen	Commissioning Manager ASC	Cornwall Council
Gill Lovell (GiL)	Carer	
Wendy Gauntlett (WG)	Carer	
Lynda Berry (LB)	Carer	
Michael May (MM)	Carer	
Gordon Lancaster (GoL)	Carer	
Esther Way (EW)	Dementia Adviser	Alzheimer's Society

APOLOGIES

Name	Organisation
Zoe Cooper	RCHT
Jason Creed	Department for Work & Pensions
Linda Byrne	Cornwall RCC
Kay Henry	Carer
Kim Hager	Cornwall Council
Mike Dann	Job Centre Plus
Susan Butterfield	Carer
Leona Thorpe	Cornwall Council
Jayne Kirkham	Cornwall Council
Angela Andrews	Cornwall Council
Jannette Smith	Cornwall Council
Helen Phillips	Action for Children
Nicola Phillips	NHS
Stacey Sleeman	Cornwall Council
Teresa Brown	Cornwall PFT
Carol Steer	NHS Kernow
Elizabeth Digweed	Action for Children

Teresa Parsons	Alzheimer's Society
Nicola McMinn	NHS
Anna Clemens	Department for Work & Pensions
Tasha Milton	Department for Work & Pensions
Kim O'Keeffe	RCH
Rob Rotchell	Cornwall Council
Jayne Price	Cornwall RCC
Kate Mitchell	NHS Kernow
Mark James	Cornwall Council
Claire Jukes	Derriford hospital
Neil Lindsay	Wadebridge and North Cornwall Carers Forum

<i>Item</i>	<i>What was discussed?</i>	<i>Action</i>
1	<p>Update from SW since last meeting:</p> <p>SW contacted Sarah Newton MP about the carer's action plan and read out a reply from her. The reply stated that she believe Universal Credit is working well for the majority of constituents and is expecting further opportunities after govt. budget is disclosed.</p> <p>SW took the Transforming Care Family Charter to the NHS Kernow governing body and all said they want to sign up to it. It isn't yet completely ratified but hopefully will go ahead. The statement SW is most concerned is followed through is "All organisations must listen to and act upon family feedback about the quality and safety of services provided to their relative". SW hopes this will be signed off by the next meeting.</p> <p>CM: Could we add something about technology and its implementation to the statement "Information must be provided in a way that is helpful and accessible to the individual and their family".</p> <p>NK: The statements in this charter are final but technology and how we use it is going to be a priority. The LDPB and CPB can write a letter of support for this charter. Can everyone take it away, think about it and get back to me with thoughts, then we can say we're in support publicly (to the NHS Kernow board).</p> <p>SC: In that case we also need to consider it for inclusion in the carers strategy.</p> <p>Review of actions from previous minutes:</p> <p>1.1 Completed 1.2 Completed 1.3 Carer's Action Plan discussed in this meeting. 1.4 SC: I've found out that we will be retendering once the contract with the current company developing the carers register runs out. Nothing will change if the company changes, the register will still exist with contact log, carers'</p>	<p>1. CPB members to send thoughts on charter to NK so the board can collectively send letter of support for charter to the NHS Kernow board</p> <p>2. NK to send write-</p>

<p>emergency cards, carers' family info</p> <p>1.5 NK: Completed</p> <p>CHC conference went ahead and feedback is positive. Write-up and Q&A from the day will be going round to PB members.</p> <p>GoL: Are all questions that were submitted going to be answered individually as was promised?</p> <p>NK: There were about 44/45 questions submitted in total. Please put together the questions you want answered and forward them to me. I'll then send them on to the CHC team and copy you in. The write-up will be shared soon so do bear in mind that your questions may be answered in this.</p> <p>GoL: I do want all questions answered. I felt the cross-PB event went very well. It was interesting to me that more than 50% of people were professionals rather than service users and carers.</p> <p>NK: Invitations went out to all members of the PBs, service users and carers had priority. It was interesting we had that mix and that so many professionals wanted to find out more.</p> <p>1.6 SC: It will be another 2 months before respite care work is started. It is to include day services.</p> <p>1.7 TOR discussed in this meeting</p> <p>1.8 To be left with NK</p> <p>1.9 Completed - We are advocating Promas's services, they are very good</p> <p>1.10 See point 1.6</p> <p>1.11 NK: I am awaiting an email from the new person responsible for commissioning specialist dental services in the SW (started post yesterday 5 November). New commissioner is called Paul Spencer.</p> <p>LB: I had a recent problem where neither my dentist nor West Country Dental Care could renew a toothpaste prescription from my GP, eventually got one but it wasn't as strong as original prescription. The GP solved it and I found out that Treliske would deal with anyone with a dental problem, but no routine check-ups. They have to have a dentist who has done additional training for specialist services.</p> <p>GiL: The two specialist dentists we had have gone private and a lot of people I know can't get check-ups for their relatives and children</p> <p>CM: Can people go to Peninsula Dental School?</p> <p>NK: The School won't take higher risk patients as they're only students</p> <p>1.12 Completed</p>	<p>up from CHC conference and Q&A to all members</p> <p>3. GL to send list of questions he wants answered in write-up to NK, to forward to CHC panel</p>
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<p>2</p>	<p>Kelvin Yates' presentation:</p> <p>2.1 Bodmin Hospital - Garner Ward</p> <p>AF: It is a major concern, several are being sent out of county due to non-movement in ward primarily due to lack of care homes that deal with that level of care needed. Chief executives from all organisations have this as a priority to heighten profile.</p> <p>SC: This is my concern in my new role (Dementia portfolio holder and commissioning manager in NHS Kernow on a secondment). Main driver is to improve diagnosis rate in Cornwall. Part of job is to understand pathway in dementia care, developing it, improving services for patients and carers.</p> <p>2.2 Carbis Bay - can't bring issues to PB for discussion</p> <p>WG: I sit on Carbis Bay forum. Only one carer turned up and the issues was about care assessments and how they wait a long time for them. I don't think this is accurate that issues aren't up for discussion at the PB. There was a concern they hadn't heard anything back but not that we can't take issues to PB.</p> <p>KY: We do then need to make sure the forums' impact is communicated</p> <p>WG: We do get more carers coming to Penzance forum, I'm trying to get more to come to Carbis bay and St Just forums from the support groups.</p> <p>2.3 Carbis Bay - length of notification time</p> <p>NK: So 6 months isn't enough. We aren't sure what's going to happen after February but we will be able to share dates after Feb in the next month</p> <p>2.4 Carbis Bay - reasonable time to wait for assessment?</p> <p>KY: Reasonable time is 3 months, and the aim is 6 weeks. There's no set time</p> <p>SC: Correct. But 3 months may not be reasonable for more high risk person</p> <p>2.5 Truro - Has previously been 3 year wait between X-ray and hip op, any solutions?</p> <p>CM: By March there will be nobody waiting between their X-ray and pre-op assessment. RCHT has been improving flow in the ED and trying to send people elsewhere if they can be treated elsewhere. We're also looking at frailty and improving information. Issues with people unable to go back to care home due to reduced capacity are improving.</p> <p>GoL: I did have an issue with a delay for hip replacement in Feb</p>	<p>4. Share CPB dates after February by mid-December</p>
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	<p>CM: It will be sorted by March</p> <p>MG: (From Derriford’s perspective) I have been in post 3 weeks now. National wait times are poor. We’re moving to Care UK (private company) north of Derriford for a lot of trauma and orthopaedics, will have a significant impact on reduction in waiting times. Next meeting I’ll have more info on the wait times.</p> <p>2.6 Specialist speakers at forums</p> <p>LB: These specialist speakers were excellent, particularly appreciated the one on PoAs</p> <p>KY: We should try and address any concerns in this way in the future</p> <p>(Difference between forum and support group: forum is semi-formal meeting with chairperson who’s ideally a CPB rep and carers can raise issues. Support group is support for carers, no chairperson, they come together and share experiences)</p>	
3	<p>Carers action plan:</p> <p>NK: It was published in 2016 so overdue for a refresh. We could probably say its statements were not achieved. Carers in Cornwall will be developing the strategy</p> <p>KY: There are 66,000 carers in Cornwall (from census and state of caring survey in 2015). We support 3,600 or 6%. Carers centres and services around the county are supporting 10%. We aren’t engaging with the rest, the ‘hidden’ carers.</p> <p>WG: We often get phonecalls from people who don’t realise they’re a carer. How long should some wait before contacting a support worker?</p> <p>KY: From the time we get any referral we respond within 10 working days, so if they haven’t heard in that time they contact a support worker.</p> <p>WG: Often people are too proud to ask for care.</p> <p>KY: We find there’s a strong sense of dis entitlement - “always someone more deserving than me”</p> <p>NK: So how do we find hidden carers?</p> <p>BE: I think young carers are more of a problem than older carers as people don’t want others to know in case social services get involved</p> <p>KD: We have groups in 19 schools at the moment and reassure them we aren’t social care. We’ve gone from spaking with 200 young carers to 1500 in 4 years.</p> <p>BE: I’m involved in YPIAG (Young People Information, Advice and</p>	5. BE to email NK the

<p>Guidance). We had this concern - I can get you in touch with them</p> <p>SC: Young people and adults carers strategies will be separate. Serena Collins will be heading the young carers strategy</p> <p>GiL: Who is running the young carers service?</p> <p>KD: it is me. I'll give you my number</p> <p>KY: KD's work is very important in raising awareness</p> <p>NK: This might be a reason for hidden carers: it isn't socially acceptable to be a carer. Carers in employment are also a hidden group as they aren't able to come to meetings, support groups. Also those with mental health issues</p> <p>MM: I have also known of cases where the cared for is unwilling to seek help and the carer is therefore hidden</p> <p>NK: May also be the case that both partners are becoming as unwell as each other and don't want to go into residential care</p> <p>SC: Yes, family members can have different needs, e.g. mental health issues for one family member and another may have physical disabilities</p> <p>NK: Also sandwich carers, intergenerational carers, mum caring for a parent and child, a parent caring for their parent and a child. They're so busy that they are hidden.</p> <p>KY: We do get a lot of sandwich carers. ¼ of people will give up full time work, 1/7 will give up work altogether</p> <p>NK: And this leads to financial hardship we're incorporating into the strategy. How do we get these hidden carers to come out? What is the benefit of calling yourself a carer?</p> <p>KY: We need to challenge the assumption that 'carer' only means a paid support worker</p> <p>WG: Absolutely right. We must advertise 'unpaid carers' can come to meetings. A hidden carer could be someone whose partner has dementia and they don't want anyone to know.</p> <p>NK: In London many communities/cultures looked upon caring for their parents and grandparents as their job and duty and so wouldn't seek help.</p> <p>SW: It's important to remember that even if your cared for is in residential care you're still managing their care and wellbeing.</p> <p>GiL: I'm no longer a 'carer'</p> <p>NK: That again is another group, if you've been caring all your adult life and suddenly aren't in that role, what do we do to</p>	<p>contact and NK to forward on to KD</p> <p>6. KD to share contact details with GiL and WG</p>
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<p>support or acknowledge these people?</p> <p>KY: The 2018-2022 strategy does mention bereavement. It's a massive adjustment and consideration.</p> <p>NK: We must acknowledge it in the strategy and the PB. How do we access the wealth of information these people have and share it. Why bother defining yourself as a carer?</p> <p>SC: It's a benefit to others, not just yourself. It is easier to say e.g. you're now entitled to carers allowance</p> <p>SW: Calling myself a carer and getting involved with Parent Carers Cornwall is very fulfilling.</p> <p>WG: Caring is the most rewarding thing I've ever done. Support worker were a big help as well.</p> <p>GiL: Paid care work is not considered a great job, partly because it isn't very well paid. This needs to change.</p> <p>NK:</p>	
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ACTION LOG:

<u>ACTION</u>	<u>RESPONSIBLE</u>	<u>COMPLETED</u>
CPB members to send thoughts on charter to NK so the board can collectively send letter of support for charter to the NHS Kernow board	All	
NK to send write-up from CHC conference and Q&A to all members	NK	Yes
GoL to send list of questions he wants answered in write-up to NK, to forward to CHC panel	GoL	Yes
Share CPB dates after February by mid-December	NK	Yes
BE to email NK the contact and NK to forward on to KD	BE	
KD to share contact details with GiL and WG	KD	

NEXT MEETING	5 th February 2018
TIME	13:30pm - 15:30pm
LOCATION	Truro