

Carer Representation Group

5 March 2019, 10.30am, Oxlease House, Hatfield

1	Present/Absent
	<p>Carers in Herts Roma Mills. Maria Kiely.</p> <p>Carer Attendees 13</p> <p>Guest Chris Badger, Deputy Director Adult Care Services.</p> <p>Apologies for Absence 3 carers</p>
2	Introductions
	<p>In the absence of MO (Chair), KM (Vice-Chair) took the chair.</p> <p>RM reported that Toby Purnell who had volunteered to take the notes of the meeting was no longer able to continue due to his health and his own caring circumstances. It was agreed to thank him for his support at previous meetings.</p> <p>The meeting then began with a round of introductions.</p>
3	Chris Badger: Co-Production and the Carers Planning and Performance Group
	<p>Chris Badger explained that as Deputy Director of Adult Care Services he has overall responsibility for Carers Services and is the lead officer on the Carers Planning and Partnerships Group (PPG). Older People's services and the Acute General Hospital social care teams also come under his remit. Additionally Chris is the Brexit lead for social care. In response to questions about the possible impact of Brexit, he advised that:</p> <ul style="list-style-type: none"> a) Hertfordshire had already experienced a loss of social care staff – particularly from Poland and the Czech Republic as the drop in the value of the pound had made working in the UK less attractive. Many have returned home or are working in Germany. b) there are an estimated 290,000 British nationals living abroad, many of whom are retired people. We cannot anticipate how many may want to return to the UK as this might depend upon the reciprocal health arrangements that may be negotiated, however a worst case scenario would be up to 28,000 coming into Hertfordshire. <p>Chris is also a member of the Adult Care Services (ACS) Co-Production Board which is co-chaired by Iain MacBeath and Leigh Hutchins (service user). The Board includes members of the ACS senior management team, representatives from Viewpoint, Carers in Herts, Age UK, Herts Care Providers Association and Healthwatch and service users and carers. The Board was set up about 2 ½ years ago to promote a co-production approach. It has done some useful work around agreeing a working definition of co-production and standards for co-producing. However the Board has, on occasions, got bogged down in a plethora of individual issues – DL confirmed that he had resigned his place because of this. Chris wants to see the Board taking a more strategic approach to ensure that stakeholders are properly involved in, for example, strategic commissioning issues but this may be done via working groups or the existing Planning and Partnerships Groups.</p> <p>Chris noted that there is wide spectrum of involvement/participation ranging from an information style 'tick box' exercise to collective participation in decision</p>

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	<p>making, involving ACS, service users and carers and service providers. It is however important to be clear about the parameters of any co-production activity – particularly in terms of finance as the Board does not control the budget available to ACS, this is a political decision.</p> <p>Chris considers that the Carers Planning and Partnership Group (PPG) is now well established and would be the right group to be involved in co-producing services that relate to carers and feeding into the Co-Production Board. The Carers Representation Group does very useful work in feeding issues into the Carers PPG – KM noted that these should be issues that relate primarily to carers but we do need to be confident that other service-related issues, e.g. relating to mental health or dementia services, are addressed by other groups within the umbrella of Co-Production. At the moment these include the Mental Health PPG, the Learning Disabilities PPG and the Dementia Strategy Implementation Group – RM noted that a new Sensory Services Strategic Partnership Board has been set up. There are however gaps in relation to Physical Disability/long term conditions and Elderly People and these need to be addressed.</p> <p>KM thanked Chris for attending the meeting and Chris said that he would be willing to come along to join in a discussion again.</p>
4	Notes of the meeting held on 5 December 2019
	The notes were agreed as a correct record.
5	Matters arising
5.1	RM reported that the two Crossroads services had said that they would aim to provide emergency cover for clients already using their services.
5.2	RM reported that it was not felt appropriate to include contingency planning via the CinH passport but that this should be raised during 1:1 Carer Planning discussions.
5.3	The issue of charging for diabetic strips had been raised at the previous Carers PPG without sufficient information to support the query, see item 7.4 below.
5.4	Councillor Fiona Hill had written out to all the agencies on the circulation list for the Carers PPG asking for representation and a response had been received from Public Health – see item 7.1 below.
5.5	WJ noted that HPCI are commissioned to deliver Parent Carer Involvement and are pleased to work in partnership with CinH.
6	Feedback from the Carers Planning and Performance Working Groups
6.1	Contingency and Lifelong Planning: MK reported that the last meeting only had three attendees and they are awaiting the next meeting date. She is chasing this. There continues to be discussion around parent carers' rights to assessment and contingency planning, particularly in the 18 – 25 client group. There has not been any focus on Long Term Planning as yet although this is an issue of great concern to many carers.
6.2	Carers Stress: this is being led by Tim Anfilogoff who sent out the following update to members of the working group in January: Dear Carer

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Piloting the Zarit Burden Tool to help us focus on reducing carer burden/stress

It was great to meet those of you who were able to join us in Hatfield in December.

Since then we have done some further work, in partnership with Surrey Heartlands and West Yorks and Harrogate STPs, who like our own Sustainable Transformation Partnership (Herts and West Essex) have been identified by NHS England as 'exemplars' in working with carers.

We had originally said that we would pull together another meeting with you before the next Countywide PPG meeting at County Hall. But we don't think there is enough additional material to make this a good use of your time, so instead I will give a quick update on where we are so far and Ted and I will take this proposal to PPG. I will be happy to hear any additional comments/questions before then, however.

1. Key Principles

- We all agreed that there is no point doing any of this work unless:*
- The 'system' takes responsibility for the stress the system itself creates for carers*
- Any such process must lead to positive change for individual carers involved – it cannot be some 'academic exercise'*
- We need to keep carers involved in developing this approach and digesting the learning*

2. National Partnership

- We have agreed with Surrey Heartlands and West Yorkshire and Harrogate STPs that we will all use the Zarit Burden Tool short form (the 12 questions we shared with you at the meeting)*
- Each site will seek to work with 100 carers, doing the questionnaire before the intervention/s and following up three months or so afterwards to see if their level of stress/burden has changed – and if so what made the difference*
- In Hertfordshire we will be looking to demonstrate that getting services to work together in an integrated way for carers/really listening to carers will help reduce their burden and stress*
- In Surrey they will be looking to demonstrate that breaks are key to reducing carer stress*
- In West Yorks they will be looking to demonstrate that supporting working carers to stay working with appropriate support can reduce their stress*

3. Hertfordshire Only

- HVCCG will continue to explore the bio-medical/fit-bit type approach to helping carers manage their stress as well, based on seeing what activities create more or less stress in their daily lives, but this thinking is in its very early stages*
- Parent carers and young carers – I think the feedback was that we need*

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	<p><i>to do more work on how best to adapt the tool for these groups, but it makes sense to try it out with adult carers first? I think there was agreement we need to engage children's services more in these discussions</i></p> <ul style="list-style-type: none"> <i>We are happy to receive suggestions for additional questions. We will have to discuss these with Professor Zarit to ensure they don't affect the validity of the tool, but we are in contact with him and he is broadly supportive of what we are doing</i> <p>JJ who attended the working group commented that the tool was very interesting but it was not clear how the findings would be used to address Carer Stress.</p> <p>KM raised the issue of barriers to sharing information about carers between HCC, the NHS and Carers in Hertfordshire and it was noted that this could be raised under item 3 of Objective 2 of the Carers Strategy Action Plan.</p>
6.3	<p>Be Safe: DL had attended one meeting but had not been notified of a further one. It was noted that the actions supporting the delivery of this objective were mainly 'Amber' which was disappointing as this is a priority issue for carers. Representatives to raise under the Carers PPG agenda item <i>Carers Strategy Action Plan – progress and plans</i>. The Group queried whether there was enough staff resource to deliver the Action Plan and agreed that representatives should also raise that concern.</p> <p>KM noted the importance in including a section on carers in any Safeguarding training for professionals.</p>
7	<p>Carers' Feedback for the Carers Planning and Performance Group (PPG) meeting on 19 March 2019.</p>
7.1	<p>Representation at the Carers PPG:</p> <ul style="list-style-type: none"> (a) the response from Public Health (PH) was noted (attached), the Group request that a representative from PH be invited to a future Carers PPG meeting to speak to the department's Commitment to Working Carers and to the wider public health issue of addressing carers' health inequalities; (b) the importance of a senior representative from the 0 – 25 service attending the Carers PPG was noted and it was agreed to request that this be secured.
7.2	<p>Carers PPG Working Groups – it was noted that there is currently no carer representation on the Social Care Practice and the Group agreed that this was a gap that should be addressed.</p>
7.3	<p>Carers Assessments and support:</p> <ul style="list-style-type: none"> (a) the Group sought clarification about which agency provides Carers Assessments and Contingency planning to carers of adults who are misusing drugs and/or alcohol; (b) the Group has previously sought clarification about which agency provides parent carer needs assessments to parent carers of young people accessing CAMHS and this remains an outstanding query. The same question is now also raised in relation to parent carers of young

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	<p>people who will access the new All Age Drug and Alcohol service.</p> <p>(c) Carers consider that times of change and transition between services can be particularly challenging to manage. This is particularly pertinent for parent carers of young adults between the ages of 18 – 25 years and it is therefore important that they are offered Carers Assessments and Contingency planning at this time. However parent carers report that they are not encouraged to seek a Carers Assessment although this is a statutory right. The Group wanted to know whether the 0 – 25 service has a policy in relation of offering parent carer needs assessments carers' assessments.</p> <p>(d) it was noted that Adult Care Services commission the Hertfordshire Partnership University NHS Foundation Trust (HPFT) to deliver Carers Assessments and Contingency planning to carers of adults with mental health issues – turnaround time and communication with HPFT staff have been raised as concerns by carers and the Group considered that Objective 1 of the Carers Strategy Action Plan should also cover HPFT's work in this area.</p>
7.4	<p>Diabetic test strips – this issue had been raised at the previous Carers PPG but there had been some confusion about the precise question. The issue is that in the Herts Valleys CCG area, carers who had previously received a prescription for the strips were now being told that they had to pay for them. One carer now has to pay £25.00 for a pack of diabetic test strips which last him about two weeks. The Group want to know when the decision was made to cease prescribing these items and whether there had been any consideration of the impact of those who rely on Benefits for their income.</p>
7.5	<p>Carers health checks – the Group asked how these checks are being funded and how they are triggered. Anecdotal report suggest that carers are not being offered a health check, even when registering with the GP surgery and not all carers will know that they need to request a check.</p>
7.6	<p>Personal Independence Payments and Employment Related Support applications – carers continue to find these processes very difficult, particularly when they reach tribunal stage. The Group noted the support offered by the Money Advice Unit and asked whether workers are still able to accompany a carer and service user to a tribunal hearing.</p>
7.7	<p>Dementia Strategy – the current Hertfordshire Dementia Strategy 2015/19 is now due for review and refresh but it is not clear when the review is planned or how carers will be involved in it.</p>
8	<p>Any Other Business</p>
8.1	<p>DL advised the Group that the Hertfordshire Partnership University NHS Foundation Trust were due to have a Care Quality Commission inspection from 6 March 2019 and the Trust is hoping to move from <i>Good</i> to <i>Very Good</i>. His carers support group has been invited to contribute to the inspection.</p>
8.2	<p>Carers Week will be from 10 – 16 June 2019. RM gave a short outline of current plans –</p> <ul style="list-style-type: none"> • Four Hub meetings • A male carers activity • Pamper session in Bushey • ? Pamper session in E&N Herts • Information session in Three Rivers

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	RM asked the Group to send in any ideas for other activities during the week.	
9	Meeting dates for the year 2019	
	Carers Representation Group	Carers PPG
	22 May 2019	4 June 2019
	28 August 2019	10 September 2019
	26 November 2019	10 December 2019
	All meetings will be held at Oxlease House, Hatfield from 10.30 – 12.30 followed by a light sandwich lunch.	