

**Partnership Group Meeting  
Tuesday 18<sup>th</sup> September 2012  
Hilton Bromsgrove**

<b>Agenda</b>	
<b>1.</b>	<b><u>Vote for new PG Chairman</u></b> <ul style="list-style-type: none"> <li>• A record taken of those present</li> <li>• A vote by those present on nominees for Chairmanship of the Partnership Group</li> </ul>
<b>2.</b>	<b><u>PG Chairman</u></b> <ul style="list-style-type: none"> <li>• Welcome to the all new Partnership Group, code of conduct and expenses</li> </ul>
<b>3.</b>	<b><u>Roger Evans, MFT Chairman</u></b> <ul style="list-style-type: none"> <li>• The Macfarlane Trust now and in the future</li> <li>• What will be the role of the next chief executive</li> </ul>
<b>4.</b>	<b><u>GRO-A</u></b> <ul style="list-style-type: none"> <li>• What is the structure and relationship between organisations at Alliance House</li> <li>• Why is there cross referencing of beneficiary personal information between these organisations</li> <li>• Is this sharing of information a breach of the Data Protection Act</li> </ul>
<b>5.</b>	<b><u>GRO-A</u></b> <ul style="list-style-type: none"> <li>• Are the MFT Board of Trustees willing to make information and details on policy making available to the beneficiary community</li> </ul>
<b>6.</b>	<b><u>PG Chairman on behave of Ian Hayes</u></b> <ul style="list-style-type: none"> <li>• The reserves exercise, how is it progressing</li> <li>• What is the timetable for completion</li> <li>• What processes will be used to award payments for the reserves to ensure they will be fair and equitable</li> </ul>
<b>7.</b>	<b><u>Mark Simmons, Senior Social Worker West Midlands Adult Haemophilia Centre</u></b> <ul style="list-style-type: none"> <li>• What are the MFT's plans to support beneficiaries who will be affected by the process of applying for or the loss of DLA/PIP payments in the near future</li> </ul>
<b>8.</b>	<b><u>GRO-A</u></b> <ul style="list-style-type: none"> <li>• How can the MFT and the beneficiary community better recognise the unique voice of women primary beneficiaries in a male dominated environment</li> </ul>
<b>9.</b>	<b><u>PG Chairman on behave of</u></b> <b><u>GRO-A</u></b> <ul style="list-style-type: none"> <li>• Should MFT staff friend beneficiaries on Face book when there is a risk of gaining information that could negatively affect a beneficiary's support from the MFT</li> </ul>
<b>10.</b>	<b><u>PG Chairman</u></b> <ul style="list-style-type: none"> <li>• Martin Harvey retirement</li> <li>• Any other business</li> </ul>

<b>1 a.</b>	<b>A record taken of those present</b>	
	GRO-A	Primary Beneficiary and Partnership Group Chairman
	GRO-A	Primary Beneficiary
	Keisha Hanchard	Support Services Officer – Macfarlane Trust
	Roz Riley	Head of Support Services – Macfarlane Trust
	Mark Simmons	Senior Social Worker – Queen Elizabeth Hospital
	Tracey Dunkley	Nurse Specialist Haemophilia - Queen Elizabeth Hospital
	GRO-A	Primary Beneficiary
	GRO-A	Primary Beneficiary – Wife
	GRO-A	Primary Beneficiary
	GRO-A	Primary Beneficiary
	Natalie Watson	Minute Taker
	Roger Evans	Macfarlane Trust Chairman
	GRO-A	Primary Beneficiary
	GRO-A	Primary Beneficiary
	GRO-A	Primary Beneficiary
	GRO-A	Primary Beneficiary
<b>1 b.</b>	<b>A vote by those present on nominees for Chairmanship of the Partnership Group</b>	
	GRO-A	asked the group if they wanted to discuss the chairmanship of the Partnership Group – the group unanimously agreed to keep GRO-A
	GRO-A	

<b>2 a.</b>	<b>Welcome to the all new Partnership Group, code of conduct and expenses</b>	
	GRO-A	distributed a handout on Code of Conduct – GRO-A requested that switching off of mobile phones be added
	GRO-A	discussed the content of the hand out, especially the paragraph regarding openness and transparency – advising that the minutes from this meeting will be available to the entire Macfarlane staff including trustees
	GRO-A	advised the group to put any travelling expenses on an expense form

<b>3.</b>	<b>Roger Evans, MFT Chairman</b>	
	Roger Evans offered congratulations to GRO-A on being voted as the Partnership Group Meeting Chairman	
	Roger Evans advised the group that he would need to leave the meeting at 3pm	
<b>3 a.</b>	<b>The Macfarlane Trust now and in the future</b>	
	Roger Evans reiterated GRO-A opening statement regarding conduct issues, advising that historical problems have been with Macfarlane Trustees, not staff, advising the way forward for good productive working must be based on mutual trust, and all working together with the same aims and objectives	
	Roger Evans gave the group a summary of his background, advising that he was previously CEO in the NHS for 13 yrs at St Georges Hospital in London,	

	<p>and 7 years for Kent Health Care 7 years. Roger Evans advised for the last 10 years he has been his own boss, specialising in Health related consultancy working closely with the NHS.</p> <p>Roger Evans told the group that when he started as CEO with St Georges, there was 25 million in the pot and by the time he left 10 years this was down to 10 million, this was considered a huge achievement as the money was actually being spent as it should be, not hoarded or invested</p> <p>Roger Evans advised he has been chairman for the Macfarlane Trust since April 2012, he advised he is very impartial to this group and is determined to work together with the Partnership Group and give as much support as possible</p>
<b>3 b.</b>	<p><b>What will be the role of the next chief executive</b></p> <p>Roger Evans advised that Martin Harvey had taken early retirement. <b>GRO-A</b></p> <p><b>GRO-A</b></p> <p><b>GRO-A</b> It was not anticipated that Martin would leave so quickly, and this has left a gap in the interim, however a decision was taken that until a replacement can be found, we have adequately skilled staff, to continue running the trust smoothly. If the other charities decide to do something differently that will be their concern.</p> <p><b>GRO-A</b> asked if the new CEO will be CEO for the whole alliance. Roger Evans advised that Claxton is in the process of appointing a new CEO, and it is ultimately easier if the Trusts go through this together as equal partners, due to the payment of staff, i.e. Macfarlane pay 40% of staff wages, including that of the CEO, Claxton also pay 40%, Skipton pay 15%</p> <p>Roger advised that the recruitment process has already started, and although it was hoped someone would be appointed pre Christmas, in reality it is more likely to be February 2013. Roger Evans and Charles Lister (Dept Chair) are seeing recruitment consultants tomorrow, and are confident that this will be productive, the role offers a competitive salary, and unlike most charities, the CEO is not responsible for raising income.</p> <p><b>GRO-A</b> addressed the subject of the massive hole Martin leaving will be to all the primary beneficiaries, and expressed the groups hope that whoever is appointed understands the need for communication and contact, both over the phone and in emails</p> <p>Roger Evans advised at this stage, there is no one earmarked for the position. One of the challenges in appointing someone is to make sure that person understands how to engage with the community they are responsible for, and the day to day challenges primary beneficiaries face.</p> <p><b>GRO-A</b> remarked that the trust primary beneficiaries had with Martin had taken years to put in place, and stressed how important it is that the new person fits into this. <b>GRO-A</b> voiced how difficult it had been contacting both Roz Riley and Keisha Hanchard on the telephone. Roger Evans advised that the telephone issue will soon be sorted out, there is the possibility of moving to the 5<sup>th</sup> floor of the building and this will involve more telephone lines, hopefully this will help</p>

	<p><b>GRO-A</b> said Martin was recognised as “a face you could trust”, he was always available for words of comfort or just to listen when you needed to discuss matters, or just get something off your chest.</p> <p>Mark Simmons advised that Martin was CEO of the Macfarlane Trust only, and was very focussed on primary beneficiaries, the other charities such as Caxton and Skipton grew, and this is when the grumbles started as the primary beneficiaries felt forgotten. Whoever is appointed as the new CEO will have no honeymoon period and the group needs to ensure that they are given enough time</p> <p>Roger Evans advised there is great merit in the charities merging, in the past it was felt that some of the Caxton trustee’s did not understand the primary beneficiaries, but now he is on board he hoped that this would no longer be the case</p> <p><b>GRO-A</b> told the group that the general impression of primary beneficiaries was that it felt like most of Roz Riley and Keisha Hanchard’s time was being taken up by Caxton, and asked Roger Evans if there was a possibility of a dedicated worker to work purely with Macfarlane Trust beneficiaries</p> <p>Roz Riley agreed that both she and Keisha Hanchard had been very busy with Caxton, however, they have now employed new staff, Keisha Hanchard is on study leave and will soon qualify as a Social Worker, which will help immensely, as she will be able to do home visits and undertake case work. Roz Riley advised that this will go out in the news letter.</p> <p>Roz advised that they are looking at the staffing situation, and they have tried to allocate and separate the new employees, 1 dedicated to Caxton, and 1 dedicated to Macfarlane Trust, this should hopefully be smoother when the new staff are fully trained. Roz Riley advised she would take this away as an action and clarify to the group.</p> <p>Roger Evans re-capped on the key issues for the Macfarlane Trust:</p> <ol style="list-style-type: none"> <li>1. The appointment of a new CEO</li> <li>2. The reserves issue</li> <li>3. Relationships with the primary beneficiaries</li> <li>4. Improving and modernisation of all the electronic communications</li> </ol>
<b>4 a.</b>	<p><b>What is the structure and relationship between organisations at Alliance House</b></p> <p><b>GRO-A</b> asked if originally MFPT Trusts 1 and 2 were under Caxton, and now the group is being told Caxton is similar to the Macfarlane Trust; how can it be umbrella.</p> <p>Roger Evans advised that Caxton is the employer of staff, and is responsible for services and facilities, i.e. the building. This was put into place by Chris Fitzgerald, who was a lawyer and advised that this was the best way to do things.</p> <p>Effectively Caxton’s role is that they are responsible for providing the services</p>

the Macfarlane Trust requires, they are not above the Macfarlane Trust and are not the authority on how things should be done. There is a service level agreement in place between Caxton and the Macfarlane Trust. Roger Evans advised he will arrange for a copy of this to be sent to **GRO-A** - Action

Roger Evans advised that a liaison committee that meets several times per year to have a dialogue of around common ground issues, arbitration issues, etc.

Roger advised that there is an MFTE body that the Department of Health gives money/funding to each year, this is the interface to government, and this money is shared between the charities. When these meetings happen Caxton and the Macfarlane trust alternate who chairs. Apart from Skipton now having an interest in staff and offices nothing has changed

Roger Evans asked Roz Riley if there were any updates purely from a Macfarlane Trust aspect on this, Roz Riley advised there were none she could recall at present, but would update the group if there were

**GRO-A** asked when this was this last reviewed?

Roger Evans advised the charity commission looked at this last year, and the final service level agreement was signed last year

Mark Simmons questioned if the service level agreement is regularly monitored and/or reviewed??

Roger Evans told the group that yes the service level agreement is regularly reviewed, and any discussions, such as a need for an increase in staff etc, has to be authorised and agreed through the service level agreement

Roz Riley advised that as the liaison committee is equally divided between Macfarlane Trust and Caxton, both sides can put their views across

**GRO-A** said it is very difficult to understand what is happening behind scenes, and this confusion breeds suspicions about how the money is shared out

Roger Evans agreed these complications, and advised hence there is a need for simplification. Roger Evans advised the group should not be too worried, as long as Macfarlane is getting services from the staff team, nothing else should concern the group. The money is all ring fenced so cant be issued where it should not be, there is no evidence of anything untoward, however, Roger advised he understands these feelings, and that this is his responsibility to ensure everything is dealt with fairly, however, if the Department of Health decided, for instance that Caxton is too generously funding and decided to give more funding to another charity such as the Macfarlane trust, no one would know.

**GRO-A** addressed a direct question to Roger Evans – saying it seems that the trustees are group of people who think what they say goes, this is how it was in the past, even though the primary beneficiaries have meetings

and agree issues, there is never any change. i.e. respite was removed primary beneficiaries had no other choice but to go to Beacon etc, this was following a meeting where all the primary beneficiaries present agreed they did not want this. This was fed back to the primary beneficiaries by Martin. **GRO-A** questioned what is point in having these kind of dialogues if they are not listened to?

Mark Simmons advised that the reason the Macfarlane Trust dropped respite, was that originally places such as Mild May or Beacon were 3 times the price of respite funding. The Macfarlane Trust are completely out of step with the rest of the organisations such as Health and Social Services, this is available for all to see under the right of information, but the Macfarlane Trust do not make the same information available.

Roger Evans addressed Mark Simmons point, advising that there will be a Board meeting on Monday 24/09/12 where he will raise this point on the group's behalf. Roger advised he will also circulation the minutes, and request that they are also put onto the website – Action

Roger Evans advised if there is to be any change; it would need to be put to the vote and a majority needed. **GRO-A** advised he has discussed going to court on this

Roger Evans advised they are looking to appoint a new trustee to replace Chris Fitzgerald. The person in mind has not long retired from another health related charity for paralysed young people. Roger Evans advised it is thought the lady in question will have an understanding of the emotional anger of those who suffer and will be someone who will engage with the primary beneficiaries. Roger Evans advised it is his vision for the future that all trustees become a lot more involved with the primary beneficiaries, he complimented Roz Riley on conveying messages between the primary beneficiaries and the trustees, but advised it requires more trustee involvement.

Roger Evans advised all trustees have a period of office they can serve, as trustees terms come to an end, different people can be brought in to replace them. It is not possible to “sack” a trustee, unless there has been a serious wrong doing.

**GRO-A** advised he has been contacted by a number of primary beneficiaries requesting that Russell Miscon be removed as a trustee, he is the epitome of what the primary beneficiaries do not want in a trustee and this should not be ignored. The letter that Russell Miscon sent out conveyed a complete lack of empathy and understanding towards the primary beneficiaries

Roger Evans advised that this is not his sole decision to make, and that if the group are serious about this then they should put their concerns in writing. Roger Evans advised as it stands Russell Miscon's term of office does not end until March 2014. Roger advised that at the last reserves meeting, both he and Chris Fitzgerald had attempted to counsel Russell regarding the letter, advising that any letter should not go out in an individual trustees name, and

	<p>should go out under the Chairman's name, however, Russell said that he had done a large amount of work on a thesis regarding primary beneficiaries and wanted letter to go out under his name. Roger Evans advised this will not happen again, and would like such things to be addressed with a meeting with the primary beneficiaries for the future.</p> <p><b>GRO-A</b> advised he was one of the recipients of the letter, and advised that the letter in question was very badly communicated, and indicated that the primary beneficiaries needed to prove they needed help and assistance. <b>GRO-A</b> advised that he spoke to Roz Riley on the matter, and that Roz helped him through this, explaining exactly why the letter was sent, and what it meant in a very empathetic way, James thanked Roz for this, and went on to say that following this he had now had a visit from a lady to assess him and he found the visit/interview very good and impartial.</p> <p><b>GRO-A</b> advised that this is a matter that needs to be discussed in more detail and will put this as an action for the next meeting. Action</p>
<b>4 b.</b>	<b>Why is there cross referencing of beneficiary personal information between these organisations</b>
	<p><b>GRO-A</b> questioned the way data is exchange within the organisation, as it seems that Caxton and Skipton have access? As some primary beneficiaries are concerned that this is happening without their consent. <b>GRO-A</b> said he would like to see an agreement signed by both parties regarding data, and also look at the Skipton 2 top up fund.</p> <p>Roz Riley advised that there is a cross reference of information only when people have given consent for this – there is a tick box saying are you happy to share data, particularly with Skipton 1 and Skipton 2, however this has not been pursued as it is difficult to establish who had what. Roz advised she would look into this with Roger Evans and feed back to the group - ACTION</p> <p><b>GRO-A</b> advised he will put this point on the agenda for the next meeting. Action</p> <p>Roger Evans advised it would be productive for the a representative from the primary group meeting to meet with the NSCC to discuss issues like this. Action</p>
<b>4 c.</b>	<b>Is this sharing of information a breach of the Data Protection Act</b>
	The group agreed they had addressed this in point 4b.
<b>5 a.</b>	<b>Are the MFT Board of Trustees willing to make information and details on policy making available to the beneficiary community</b>
	<p><b>GRO-A</b> questioned Roger Evans as to why exactly reserves were never spent in past and now primary beneficiaries have to go after the money?</p> <p>Roger Evans advised that this goes back to 2005 and then funds were built up in 2 ways:</p> <ol style="list-style-type: none"> <li>There was a feeling that reserves should be kept in case the Department of Health made a cut to allocations</li> <li>Trustees felt reserves should be kept as returns on investments</li> </ol> <p>Roger Evans explained he does not know why it happened like this, as he</p>

	<p>was not in position then, but advised he will discuss this with Peter Stephens</p> <p><b>GRO-A</b> advised that it was thought that one year's expenditure was kept back in case the Department of Health pulled the plug on benefits</p> <p>Mark Simmons advised that this was due to a risk of adverse policy, and interpretation over what it cost to run for a year, again this is a very grey area, as it is almost a case of if Macfarlane can prove to the need for more money to the Department of Health they will give it.</p>
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<b>6 a.</b>	<b>The reserves exercise, how is it progressing</b>
	<p>Mark Simmons reminded the group that the looking at the reserves is likely to be a huge piece of work, a lot of this will fall to Roz Riley and Keisha Hanchard, they already take a lot of work on, and this will impact on the problem with contacting them by telephone.</p> <p>Mark Simmons told the group to bear in mind what has already been discussed at this meeting, and wait and see how the trust role this out, there will be a new CEO in place soon and things will inevitably change,</p>
<b>6 b.</b>	<b>What is the timetable for completion</b>
	Roger Evans advised that this should be done by the end of the month
<b>6 c.</b>	<b>What processes will be used to award payments for the reserves to ensure they will be fair and equitable?</b>
	<p>Roger Evans advised Equal MC will have interviewed over 200 people, of those 30 primary beneficiaries of the Macfarlane group were shortlisted for interview. Roz Riley and Keisha Hanchard have done just under 250 jointly.</p> <p>Roz Riley advised in a recent meeting with Equal MC recently the subject of carrying on, adding more people was discussed, but no figure was put on this. Initially the idea was that an independent body would do this, this did not happen. The has been done has made it inequitable, as one group of people have been processed in one way, and another group differently.</p> <p>Roger Evans asked Keisha Hanchard if the 30 people contacted were interviewed by independent person, if not Roger Evans will take this back to Equal MC. Action</p> <p>Roger Evans advised Equal MC had virtually finished and Pie charts will be available once a significant amount of interviews have been done. The money that is needed is in the sum of 5.7 million which reserves do not have. Roger advised that he and Martin had put together a briefing paper to the Department of Health on 25/07/12 and as a result of this the Department of Health wanted a full Business case by the end of October 2012, this will then be given to Anne Milton, the Government Minister in November 2012.</p> <p>Mark Simmons reminded the group that if any primary beneficiary has any real priority issues, they should submit their requests through the normal Macfarlane trust channels and not the reserve.</p> <p><b>GRO-A</b> asked if it was possible for clarification to be given to all on what the emergency grant process is. <b>GRO-A</b> advised he would put this as a point for the next meeting, and advised to address this in letter format. Action</p>



	<p>Mark Simmons advised that an assessment is about a need not about money and in the past. Historically they have had to advocate on behalf of the primary beneficiaries and challenge trustees in the pasts, but the real issue is lack of information. Mark advised that they still do a lot of work with widows of primary beneficiaries who are terrified to move as there is a debt from when their partner was alive still attached to the house. Roger Evans advised this is an area he would look into and suggested further discussion it at the next meeting. Action</p> <p><b>GRO-A</b> asked regarding the Equal MC interviews, commenting that approx. 250 had agreed, but how many had refused to take part? Roger Evans advised the figure was approx. 600, but in order for them to prove a business case to the Department of Health 250 was enough</p> <p><b>GRO-A</b> advised that the letters were not clear, and work interview not understood. <b>GRO-A</b> stated it felt like you had to establish a need and was very similar to how things were done 10 years+ ago.</p> <p><b>GRO-A</b> thanked <b>GRO-A</b> for raising this point, stating that this situation will arise again and should be dealt with now.</p> <p>Roger Evans advised he had taken on board what was being said, and would feed back to the trustees. When it is known where we all are with money, he wants to work together as team and come up with a proposal.</p>
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<b>7.</b>	<p><b>What are the MFT's plans to support beneficiaries who will be affected by the process of applying for or the loss of DLA/PIP payments in the near future</b></p>
	<p>Mark Simmons advised that the Government is capping all benefits, PIP will replace DLA and when Universal benefit comes in it is sadly expected that everyone will receive less. At this stage there is no clarity, no one knows what are the tools that will be used to make assessments or on what basis, if people fail the transition from DLA to PIP this could also affect car benefit meaning car tax, and insurance will also become liable.</p> <p>Mark Simmons advised this is not just this group of primary beneficiaries but everyone on benefits.</p> <p>Mark Simmons asked it to be put to the Macfarlane Trust that while the reserve is still here, can some of it be ring fenced until it is known exactly what is happening once PIP is in place.as the requirements are not understood, and if someone is turned down, we will not know how to appeal until it happens</p> <p>Roz Riley advised that they had reviewed DLA and did implement short term assistance while looked it was looked at, it is now apparent that this will affect more people than originally thought so the cost implications will be more. In order to request more money be made available the Trust will want to know figures, timeframes etc. Roz Riley and Mark Simmons agreed to liaise with Neil Bateman and put together a document to present to the board in such a way that the trustees understand the impact to a primary beneficiary if they</p>

	<p>lose a benefit. Action</p> <p><b>GRO-A</b> asked if there would be any merit in having a dedicated meeting on this subject. Mark Simmons advised that at the moment this would just be hypothetical, as until it is know exactly how the Government plan to change things it would just be discussing the unknown. Mark advised Lord Archer and Lord Morris, both great supporters, that now is the time for all primary beneficiaries and those on benefits to write to their MP.</p> <p>Mark Simmons advised that the PIP pilot next year will succeed, it will be a case of anyone new coming onto benefits will go directly onto it, whilst existing people on benefits will migrate to it over a period of time due to the vast amount of cases. Mark Simmons asked it to be shared that any primary beneficiary who's DLA is questioned should be advised to contact the Macfarlane Trust, there is no need to panic, but the trust need to know. Roz Riley advised this would be added to the newsletter. Action</p>
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<b>8 a.</b>	<p><b>How can the MFT and the beneficiary community better recognise the unique voice of women primary beneficiaries in a male dominated environment</b></p>
	<p><b>GRO-A</b> said she wanted women to be recognised, and advised that there are 42 female primary beneficiaries. She discussed the women only weekends, and wanted to promote the benefits of such weekends, asking it to be understood that women primary beneficiaries had different issues to male beneficiaries but they should not be lessened because of that</p> <p>Keisha Hanchard advised that the women only weekends were a lot more informal to the men's "something for the weekend", and proved a great help for those women that did attend.</p> <p>Mark Simmons advised that all weekends had been revamped recently, and were a lot more holistic and therapeutic. Mark suggested raising any issues between separate groups at the next men only weekend</p> <p><b>GRO-A</b> advised that within the group there are many different kinds of primary beneficiaries, and we should also not forget those bereaved</p> <p>Roger Evans advised he had to leave the meeting, and gave thanks to <b>GRO-A</b> and the group. Roger advised he would address this at the board meeting on Monday.</p> <p><b>GRO-A</b> advised the group that historically the Partnership Group chairman could make a report at the Board, but Roger Evans had advised that as this was Monday, it was too short notice so he would provide Roger Evans with a written summary and a full copy of the minutes to present. Roger Evans agreed – ACTION</p>

<b>9 a.</b>	<p><b>Should MFT staff friend beneficiaries on Face book when there is a risk of gaining information that could negatively affect a beneficiary's support from the MFT?</b></p>
	<p><b>GRO-A</b> advised this agenda item was raised on behalf of <b>GRO-A</b> and was centred around the fact that not everyone was familiar with face book complex security settings and therefore should the Macfarlane</p>

	Trust have a Face book page
	The group had a lengthy discussion, but no agreement could be obtained. The group agreed for this to be taken up at the next forum. Action

<b>10 a.</b>	<b>Martin Harvey retirement</b>
	<p>GRO-A told the group that Martin had asked that a few words were passed on, "he is very pleased to have known you all, he wished you all the very best for future, and never let the buggers grind down"</p> <p>GRO-A voiced the primary beneficiaries feelings that Martin has left a massive hole for the new CEO to fill</p>
<b>10 b.</b>	<b>Any Other Business</b>
	<p><b>GRO-A – MSPT 2 Payments</b></p> <p>GRO-A reminded the group that these initial payments were pre the Macfarlane Trust being set up, there was initially for MSPT1 and MSPT2, and this was a scaled payment based on circumstances i.e. dependants, married couples, children etc. GRO-A suggested that this should now be re-visited and reviewed on primary beneficiaries present circumstances.</p> <p>Mark Simmons advised that this was a subject that had been debated a lot over years; it should have been given out at one level payment, up to the highest level.</p> <p>Roz Riley advised GRO-A that he should put this subject to the trustees, advising that this should be in a documented format, showing figures and input from primary beneficiaries. Action</p> <p>GRO-A advised that to do this as much interest as possible needs to be generated and primary beneficiaries need to be encouraged to come forward and discuss. GRO-A suggestions so that a sound decision can be made.</p> <p>Mark Simmons advised in the past the board has proved to listen advising of a case of discrimination that was taken to the board in about 2003 and the decision changed</p> <p>Keisha Hanchard advised that if a proposal were put forward it would be looked at everyone being infected not age, or dependants etc. Mark Simmons advised that in reality the Macfarlane Trust could not pay such a bill without going back to the Department of Health for more money</p> <p>GRO-A told the group he had sat on the board for 7 years, and certain trustees do not understand the problems primary beneficiaries face. The Partnership Group needs to be strong if they want things they are not happy with to change, but they also need to understand how to put together to present to the trustees.</p> <p>Mark Simmons requested that the minutes from this meeting are put onto the website so all primary beneficiaries can see and comment if they wish, as this would raise awareness, GRO-A agreed this and also asked Roz Riley to provide a printed version if requested by those without the internet. Action</p>

<p><b>GRO-A</b> asked if the Partnership Group could have a separate mailing budget. Keisha Hanchard advised she will discuss this with Linda. ACTION</p> <p>Roz Riley advised there is a Trustee's board meet on Monday, and will add this point</p> <p><b>GRO-A</b> asked if it had been established when contact between the Partnership group and the trustees would be. <b>GRO-A</b> advised that that Roger Evans will raise this point as an agenda point at the next meeting. Action</p> <p><b>GRO-A</b> advised he will give Roger Evans a copy of the full minutes of this meeting and a written statement. Action</p> <p>Mark Simmons advised that we should take note of when the Board meetings are in order for points and/or actions discussed at the Partnership Group meeting to be added to their agenda</p> <p><b>GRO-A</b> – Martin Harvey</p> <p>Regarding Swindon, both the stone and bench in a need of repair, could the trustees be asked for funding - All agreed - Action</p>
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Actions Agreed		
Action	Person Responsible	Timescale
3b. To clarify if a new member of staff can be dedicated to the Macfarlane Trust once fully trained	Roz Riley	1 week
4a. Roger Evans to arrange for a copy of the service level agreement between Caxton and the Macfarlane Trust to be sent to <b>GRO-A</b> - Action	Roger Evans/Roz Riley	1 week
4a. Roger Evans to raise the respite point at the Board meeting on Monday 24/09/12, circulation the minutes, and request that they are also put onto the website	Roger Evans	1 week
4a. Reserve payments	<b>GRO-A</b>	Next Meeting
4b. Look at sharing of data, feedback to <b>GRO-A</b> <b>GRO-A</b> to bring up at the next meeting	Roz Riley/Roger Evans	Next Meeting
4b. To advise <b>GRO-A</b> when the NSCC are next meeting and extend an invite to him, or a representative from the primary benefits group	Roger Evans	1 week
6c. To see if 30 Macfarlane Trust primary beneficiaries were interviewed by independent person	Keisha Hanchard/Roger Evans	On-going
6c. To clarify the emergency grant process	<b>GRO-A</b>	Next meeting
6c. Dependants and Bereaved	Roger Evans/ <b>GRO-A</b> <b>GRO-A</b>	Next Meeting
7. Roz Riley & Mark Simmons to put	Roz Riley/Mark	

together a document requesting ring fencing of reserve money	Simmons	
7. To put advise on the newsletter for any primary beneficiary who has their DLA questioned	Roz Riley	Before the next newsletter
8. & A.O.B To raise discussions between the trustees and the Partnership Group as an agenda point at the Board meeting and discuss the points raised at this meeting	Roger Evans	24/09/12
8. & A.O.B To provide a written summary and copy of the minutes of this meeting to Roger Evans	GRO-A	24/09/12
9. On the subject of Facebook, and a Macfarlane Trust having a Facebook page – the group all agreed for this to be brought up at the next forum	GRO-A / Roz Riley	In line with the next forum meeting
A.O.B Put together a viable document showing figures and primary beneficiary input on the subject of reviewing the MSPT payments	GRO-A	On-going
A.O.B Minutes of the meeting to be put on the website so all primary beneficiaries can see and comment if they wish. A printed version available if requested	Roz Riley	On-going
A.O.B Separate mailing budget for the Partnership Group	Keisha Hanchard	On-going