Partnership Group Meeting Tuesday 18th September 2012 Hilton Bromsgrove

	Agenda
1.	Vote for new PG Chairman
	A record taken of those present
	A vote by those present on nominees for Chairmanship of the
	Partnership Group
2.	PG Chairman
	Welcome to the all new Partnership Group, code of conduct and
	expenses
3.	Roger Evans, MFT Chairman
	The Macfarlane Trust now and in the future
	What will be the role of the next chief executive
4.	GRO-A
	What is the structure and relationship between organisations at
	Alliance House
	Why is there cross referencing of beneficiary personal
	information between these organisations
	Is this sharing of information a breach of the Data Protection Act
5.	GRO-A
	Are the MFT Board of Trustees willing to make information and
	details on policy making available to the beneficiary community
6.	PG Chairman on behave of Ian Hayes
	The reserves exercise, how is it progressing
	What is the timetable for completion
	What processes will be used to award payments for the reserves
	to ensure they will be fair and equitable
7.	Mark Simmons, Senior Social Worker West Midlands Adult Haemophilia
	<u>Centre</u>
	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
8.	GRO-A
	How can the MFT and the beneficiary community better recognise
	the unique voice of women primary beneficiaries in a male
	dominated environment
9.	PG Chairman on behave of GRO-A
	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
10.	PG Chairman
	Martin Harvey retirement
	Any other business

1 a. A record taken o	f those present
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
1 b. A vote by those	present on nominees for Chairmanship of the
Partnership Grou	
	ed the group if they wanted to discuss the chairmanship of
the Partnership G	roup – the group unanimously agreed to keep GRO-A

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

3.	Roger Evans, MFT Chairman
	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
3 a.	The Macfarlane Trust now and in the future
	Roger Evans reiterated GRO-A opening statement regarding conduct
	issues, admitting to historical problems with communication and agreeing 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; 6 years at St Georges Hospital in
	London, and 7 years for Mid Kent Healthcare NHS Trust. Roger Evans advised for the last 10 years he has been his own boss, specialising in Health

[related consultancy working closely with the NHS.
	related consultancy working closely with the Nino.
	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 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.
	Roger Evans advised he has been chairman for the Macfarlane Trust since April 2012 and is determined that the board work together with the Partnership Group and give as much support as possible to each other.
3 b.	What will be the role of the next chief executive
	Roger Evans advised that Martin Harvey had taken early retirementGRO-AIt was not anticipated that Martin would leave soquickly, and this has left a gap in the interim, however a decision was takenthat until a replacement can be found, there are adequately skilled staff tocontinue running the trust smoothly.If the other charities decide to dosomething differently that will be their right.
	GRO-A asked if the new CEO will be CEO for the whole alliance. Roger Evans advised that Caxton 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. The new CEO will be for the MFT, Caxton, Skipton and Eileen Trusts.
	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. Recruitment consultants will be appointed and he is confident the CEO post will attract good candidates.
	GRO-A addressed the subject of the massive hole Martin leaving will be to all the primary beneficiaries, and expressed the group's hope that whoever is appointed understands the need for communication and contact, both over the phone and in emails
	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.
	GRO-A 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. GRO-A 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 th floor of the building and this will involve more telephone lines, hopefully this will help
	GRO-A 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.
	Mark Simmons advised that Martin was CEO of the Macfarlane Trust only, and was very focussed on primary beneficiaries; that 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 to bed themselves in.
GRO-A 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
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 newsletter.
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.
 Roger Evans re-capped on the key issues for the Macfarlane Trust: 1. The appointment of a new CEO 2. The reserves issue 3. Relationships with the primary beneficiaries 4. Improving and modernisation of all the electronic communications

4 a.	What is the structure and relationship between organisations at Alliance House
	GRO-A asked if MSPT Trusts 1 and 2 now fall under the umbrella of Caxton, and also as Caxton's grant-making structure is similar to the Macfarlane Trust; how can it be the umbrella organisation for all the Alliance charities including Macfarlane.
	Roger Evans advised that Caxton is the employer of staff, and is responsible for services and facilities, i.e. the building. The MFT cannot legally trade services with other organisations and there was no alternative but for Caxton to become the employer. This was put into place by Chris Fitzgerald, who as a lawyer advised that this was the best way to do things.
	Effectively Caxton's role is that they are responsible for providing the services 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 around common-ground issues.

Roger advised that the MFET is the body to which the Department of Health gives money/funding to each year, this is the interface with 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 the 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 funded 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; that this is how it was in the past, even though the primary beneficiaries have meetings and agree issues, there is never any change. e.g. respite grants were removed and primary beneficiaries had no other choice but to go to specialist respite centres such as 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 Evans said he would ask the Board to consider circulating minutes on the website.

ACTION

Roger Evans advised if there is to be a 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.

GRO-A advised he has been contacted by a number of primary beneficiaries requesting that Russell Mishcon 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 Mishcon sent out conveyed a complete lack of empathy and understanding towards the primary beneficiaries

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. Roger Evans advised that it is not his decision to make, and that if the group are serious about this then the appropriate thing to do is put their concerns in writing.

GRO-A 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. **GRO-A** 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, <u>GRO-A</u> 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.

GRO-A 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
4 b.	Why is there cross-referencing of beneficiary personal information
	between these organisations
	GRO-A questioned the way data is exchange within the organisation, as it seems that Caxton, Skipton and Macfarlane have access to each other's data. Some primary beneficiaries are concerned that this is happening without their consent. Andrew said he would like to see an agreement signed by both parties regarding data, and also look at the way the Skipton 2 payments affect the Macfarlane top-up payments.
	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
	GRO-A advised he will put this point on the agenda for the next meeting ACTION
	Roger Evans advised it would be productive for the a representative from the Partnership Group to meet with the NSSC to discuss issues like this.
4 c.	Is this sharing of information a breach of the Data Protection Act
	The group agreed they had addressed this in point 4b.

5 a.	Are the MFT Board of Trustees willing to make information and details on policy making available to the beneficiary community
	GRO-A questioned Roger Evans as to why exactly reserves were never
	spent in past and now primary beneficiaries have to go after the money?
	Roger Evans advised that this goes back to 2005 before he was a Trustee. He understands funds were built up in 2 ways:
	 There was a feeling that reserves should be kept in case the Department of Health made a cut to allocations
	ii. Trustees felt that funding accumulated through return on investments should be kept as reserves
	Roger Evans explained he does not know why it happened like this, as he was not in position then, but advised he will discuss this with Peter Stevens. GRO-A advised that it was thought that one year's expenditure was kept back in case the Department of Health pulled the plug on funding
	Mark Simmons advised that this was due to a risk averse policy, and interpretation over what it cost to run for a year, again this is a very grey area, as it is almost certainly a case that if Macfarlane can prove to the Department of Health the need for more money they will release it.
6 a.	The reserves exercise, how is it progressing
	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

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	Hanchard, they already take a lot of work on, and this will impact on the problem with contacting them by telephone.
Gh	Mark Simmons told the group to bear in mind what has already been discussed at this meeting, and wait and see how the trust roll this out, there will be a new CEO in place soon and things will inevitably change,
6 b.	What is the timetable for completion
C -	Roger Evans advised that this should be done by the end of the month
6 c.	What processes will be used to award payments for the reserves to ensure they will be fair and equitable?
	Roger Evans advised =MC will have interviewed over 200 people out of around 250 applications. There are around 50 primary beneficiaries of the Macfarlane group who have fallen outside this contracted amount. Roz Riley and Keisha Hanchard will take on the responsibility of performing these extra interviews.
	Roz Riley advised in a recent meeting with =MC, the subject of extending the contract to cover more interviews was discussed, but no figure was put on this. Initially the idea was that an independent body such as =MC would do all of the interviews, but this has not happened. This makes the process inequitable, as one group of people have been processed in one way, and another group potentially differently.
	Roger Evans asked Keisha Hanchard if the 50 people outstanding could be contacted and asked if they would prefer to be interviewed by =MC rather than Trust staff. If so Roger Evans will take this back to =MC.
	Roger Evans advised =MC had virtually finished their initial calculations and the money that is needed is in the region of £5.7 million which exceeds the available reserves significantly. 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.
	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 grant-making channels and not the reserves.
	GRO-A asked if it was possible for clarification to be given to all on what the emergency grant application process is. GRO-A advised he would put this as a point for the next meeting, and advised that there was a letter circulated addressing this issue that he would find for the next meeting. ACTION
	Mark Simmons advised that an assessment is about a current need, not about money granted in the past. Historically they have had to advocate on behalf of the primary beneficiaries and challenge trustees in the past, 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 house 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 at the next meeting.

ACTION

GRO-A asked regarding the =MC interviews that although 250 had agreed, how many had refused to take part? Roger Evans said very few but advised the total beneficiaries approached was approx. 600, but in order for them to prove a business case to the Department of Health 250 was enough

GRO-A advised that the letters were not clear, and how the interview would work was not understood. **GRO-A** stated it felt like you had to establish a need and was very similar to how things were done 10 years+ ago.

GRO-A thanked **GRO-A** for raising this point, stating that this situation will keep on arising and should be dealt with now.

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.

GRO-A raised the issue about how Widows and Bereaved are communicated with and whether or not they would have been informed about the PG meeting. Roz Riley advised that the bereaved community did not receive the regular newsletter or an invitation to Something for the Weekend and would therefore not have received information on the PG meeting. **GRO-A GRO-A** asked if it could be taken back to be discussed whether the bereaved community could in future be informed fully of PG meetings and also invited to events such as Something for the Weekend or similar. It was decided that this would be looked into.

ACTION

7.	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
	Mark Simmons advised that the Government is capping all benefits, PIP will replace DLA and when Universal Credit 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 are 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 benefits such as Mobility Allowance/Motability cars, and will also mean beneficiaries will become liable to pay car tax and insurance.
	Mark Simmons advised this is not just this group of primary beneficiaries but everyone on benefits.
	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

Roz Riley advised that during past reviews of DLA the MFT did implement short term assistance while applications were under appeal. 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 lose a benefit.

ACTION

GRO-A 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 known exactly how the Government plan to change things it would just be discussing the unknown. Mark advised that with the sad news of the deaths of Lords Archer and Morris, both great supporters, that now is the time for all primary beneficiaries and those on benefits to write to their MP.

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

8 a.	How can the MFT and the beneficiary community better recognise the unique voice of women primary beneficiaries in a male dominated
	environment
	GRO-A 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
	Keisha Hanchard advised that the Women Only Weekends were a lot more informal than the Men Only and Something for the Weekend events, and proved a great help for those women that did attend.
	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 Something for the Weekend
	GRO-A advised that within the group there are many different kinds of primary beneficiaries, and we should also not forget those bereaved
	Roger Evans advised he had to leave the meeting, and gave thanks to GRO-A GRO-A and the group. Roger advised he would address this at the board meeting on Monday.
	GRO-A 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

9 a.Should MFT staff friend beneficiaries on Facebook when there is a risk
of gaining information that could negatively affect a beneficiary's
support from the MFT?GRO-Aadvised this agenda item was raised on behalf of
GRO-AGRO-Aadvised this agenda item was raised on behalf of
GRO-AGRO-Aand was centred around the fact that not everyone was familiar with
Facebook's complex security settings and therefore should the Macfarlane
Trust have a Facebook pageThe group had a lengthy discussion, but no agreement could be obtained.
The group agreed for this to be taken up on the forum.

ACTION

10 a.	Martin Harvey retirement
10 a.	GRO-A told the group that Martin had asked that a few words were
	tord the group that martin had denod that a for morde more
	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 you down"
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	GRO-A voiced the primary beneficiaries' feelings that Martin has left a massive
	hole for the new CEO to fill
10 b.	Any Other Business
	GRO-A – MSPT 2 Payments
	GRO-A reminded the group that these initial payments were pre the
	Macfarlane Trust being set up, there was initially a £20,000 MSPT1 payment
	across the board and a scaled MSPT2 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.
	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 of payment, up to the
	highest level.
	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
	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.
	Mark Simmons advised in the past the board has been persuaded to listen to
	requests made on this subject, advising of a case of discrimination that was
	taken to the board in about 2003 and the decision changed

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	
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 presentations to the trustees.	
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.)
GRO-A asked if the Partnership Group could have a separate mailing budget. Keisha Hanchard advised she will discuss this with Linda.	an a
Roz Riley advised there is a Trustees board meet on Monday, and will add this point	
GRO-A asked if it had been established when contact between the Partnership group and the trustees would be. GRO-A advised that that Roger Evans will raise this point as an agenda point at the next meeting. ACTION	
GRO-A advised he will give Roger Evans a copy of the full minutes of this meeting and a written statement ACTION	1
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	
GRO-A <u>— Martin Harvey</u> Regarding Swindon, both the stone and bench are in need of repair, could the trustees be asked for funding - All agreed	ł
ACTION	0000X