
	<p>Learning Disability Programme Board</p> <p>Note of the Meeting Date - 4 July 2013 Time - 1.30-4.30pm Venue - The Boardroom, Richmond House</p>
 	<p>Chairs:</p> <p>Norman Lamb, Minister for Care and Support</p> <p>Jon Rouse, Director General for Social Care, Local Government and Care Partnerships at the Department of Health</p>

People who were at the meeting:

Karen Flood - National Forum of People with Learning Disabilities
(Supported by Paula Camborne)

Craig Hart - National Forum of People with Learning Disabilities
(Supported by Catherine O'Byrne)

Vicki Raphael - National Valuing Families Forum (NVFF)

Viv Cooper - NVFF and the Challenging Behaviour Foundation (CBF)

Jan Tregelles - Mencap


Ciara Lawrence – Mencap (Supported by Ailis Hardy)

Alan Rosenbach – Care Quality Commission

Alick Bush - The Learning Disability Professional Senate
 Chris Bull - Joint Improvement Team
 Ivan Ellul - NHS England
 Sam Cramond – NHS England
 Andrea Pope-Smith - ADASS
 Bill Bentley – Local Government Association
 Chris Welsh – Health Education England
 Howard Bines - Department for Business, Innovation and Skills
 Helen Nix - Department for Education
 John Skinner – Department Work & Pensions
 Bruce Calderwood – Department of Health
 Frances Smethurst - Department of Health
 John Crook - Department of Health
 Anne Spence - Department of Health
 Pam Nixon – Department of Health
 Mark Bennett – Department of Health
 Zavar Patel – Department of Health
 Anita Wadhawan – Department of Health
 Amy Key – Department of Health
 Emily Runcorn – Department of Health (Secretariat)


People who were not at the meeting (apologies):

Tim Breedon - NHS Confederation
 Rosy Pope – ADASS
 Bill Mumford - Providers Forum and TLAP
 Ann Marie Connolly – Public Health England
 Ben Thomas – Department of Health
 Rachel Holynska – Department of Health

	<p>1. Introductions and welcome</p>
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1.1 Jon Rouse introduced himself and then members introduced themselves around the table. Jon told the Board about his recent visit to Changing our Lives in Dudley and he invited members to suggest future visits so that he can see projects first-hand. He noted concerns that the agenda seemed to be narrowing from the times of Valuing People Now. He said that over time a better balance will be achieved as it was important not to focus only on Winterbourne View.


ACTION 1: Members are requested to suggest visits to projects/programmes for Jon Rouse.

	<p>2. Minutes of meeting on 7 March 2013</p> <p>What has happened on the actions we agreed at the last meeting?</p>
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2.1 Jon went over the action points from the last Learning Disability Programme Board meeting on 7 March 2013, which had all been completed:

Number	Action	Owner	Update
1	Frances Smethurst to revise governance slide to make the relationships between the boards very clear for people to see.	Frances Smethurst	Complete - Included in Statement of Accountability (item 4 on agenda)
2	NHS England to consider what further assurance is needed about actions at a local level.	Ivan Ellul	Complete - LA stocktake should provide further information (item 5 on agenda)
3	Gavin, Viv and Andrea to be	Emily	Complete – all

	invited to Provider Roundtable on 26 th March	Runcorn	attended
4	Chris Bull and Zavar Patel to link up work with the Joint Improvement Programme on key performance indicators and audit.	Zavar Patel	Complete - Update will be given in Information and Data workstrand update (item 6)
5	Find out about local government data issues as part of working group – Data & Info Group	Zavar Patel	Complete - Update will be given in Information and Data workstrand update (item 6)
6	Ivan Ellul said that he is sending a letter to Health and Wellbeing Boards so that they will be involved at a local level and hold Local Authorities and Clinical Commissioning Groups to account.	Ivan Ellul	Letter sent from Minister in May. Copy sent to LDPB members via email.
7	John will change the language in the Communications strategy to remove “users” and “actors” because this is not appropriate.	John Crook	Complete
8	Pam Nixon to speak to Viv about restraint and PBS	Pam Nixon	Complete - Viv was part of the working group meeting on 11 th June.

	<p>3. Terms of Reference (revised)</p> <p>What the Learning Disability Programme Board is for</p>
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3. Terms of Reference (revised)

3.1 Frances Smethurst introduced the Terms of Reference (ToR) of the Learning Disability Programme Board (paper LDPB(13)17), which has been revised slightly since the Winterbourne View report. Frances asked members to look particularly at paragraphs 10-12 which set out the role of a Board member including passing on information to their organisations about what had been discussed at Board meetings.

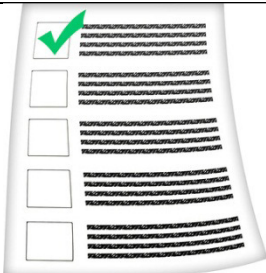
3.2 Viv Cooper commented that the ToR was quite passive and should be phrased in terms like “influencing, shaping, co-production”. Viv also said that it was very important that Government policies translate into improved outcomes for people with learning disabilities.

3.3 Craig Hart commented that the last sentence of paragraph 1 should be changed to “This should include: housing, changes to benefits, education and jobs”.

3.4 Chris Bull commented that the ToR should reference children specifically.

3.5 It was agreed that the ToR will be worked on further and recirculated to Board members.

ACTION 2: Frances to make changes to ToR and re-circulate to the Board

	<p>4. Draft Statement of Accountability – Post Winterbourne View</p> <p>Who is responsible for what?</p>
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4.1 Frances said that the points raised in the pre-meeting with the Fora had been taken on board and so it reflected accountability to people with learning disabilities and their families (paper LDPB (13)18). Frances also said that the statement should provide information to reflect the changes on 1 April to the Department of Health (DH), NHS England, Health Education England and changes at the Care Quality Commission (CQC). Frances said that wording has been used from existing publications to keep consistency and that some of the membership lists needed updating and asked people to send their up-to-date lists.

4.2 Vicki Raphael pointed out that some groups do not have people with learning disabilities or family carers involved. Vicki offered to present the work and vision of the National Valuing Families Forum (NVFF) at the next meeting which was accepted by Jon Rouse.

ACTION 3: Members responsible for any of the membership lists in the Statement of Accountability (NHS England Winterbourne Steering Group, Joint Improvement Board, CQC Learning Disability Advisory Group, Learning Disability Professional Senate) should send updated lists to the Secretariat.

ACTION 4: Include an item on the agenda at the next Board meeting for the NVFF and the National Forum to present their work and vision.

4.3 Karen asked if photos of Board members could be collected and circulated.

ACTION 5: Board members to send a photo to the Secretariat.


4.4 Jon Rouse added that Health and wellbeing boards need to be included to show local level accountabilities. He also thought that there should be something about Healthwatch and that the Learning Disability Professional Senate should be included. Alan Rosenbach commented that the two Forums should be included in the Statement.

ACTION 6: Frances to add both Forums to the Statement of Accountability, information on Health and Wellbeing Boards and Healthwatch, and include the Learning Disability Professional Senate.

4.5 There was some further discussion around getting it right for children and whether the Department for Education should be included in the Statement of Accountability. Anne Spence said that there is a Children's Partnership Board which is the equivalent Board to the Learning Disability Programme Board (LDPB) and also the reformed Children and Young People's Outcomes Forum which is now chaired by Christine Lenehan from the Council for Disabled Children. Craig Hart requested that there should be a representative from the LDPB on the Children's Board.

ACTION 7: Request someone from LDPB to sit on Children's Partnership Board when relevant issues are discussed. Anne Spence to discuss with the Children's Partnership Board

4.6 Alick Bush was concerned about how the statement of accountability would be used. Frances said that all the papers are available on the gov.uk website so that anyone who wants to can look at this document. Jon Rouse said the Board can use it to hold each other to account.

	<p>5. Reports from Key Delivery Partners</p> <p>This is what the main organisations said they are doing to improve people's care.</p>
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Update from NHS England

5.1 Ivan Ellul updated that there had been good progress on commitments for May/June but that NHS England need to focus on quality assurance. Ivan talked through the slides (paper LDPB (13)26) covering information on registers and reviews.

5.2 There was some discussion about the difference in the number of people receiving a review and the numbers in previous publication including *Transforming Care*. The Minister said that definitions should not stop including everyone who should be reviewed and that reviews might need to be expanded to a wider group of people. Chris Bull said the Joint Improvement Programme's role is to go beyond definitions and to make sure people are getting the right care in the right place.

5.3 Andrea Pope-Smith said that she had been the contact for issues from providers and common themes were that the definitions had been inconsistently applied, particularly to forensic placements.

5.4 Alan Rosenbach said that in spite of problems with definitions, this had not stopped reviews from happening and the process will become more refined. Ivan said that there will be further data to follow with the Local Authority stocktake being analysed by the Joint Improvement Programme (JIP) and the rerun of the Count me in census for learning disability providers later in the year.

5.5 Vicki Raphael said that the test is good outcomes and that it is not just about good process. She also commented that the transition from childhood to adulthood needs to be tracked as this will have an impact. Ivan responded that an age profile will be produced.

5.6 Ciara Lawrence asked the Minister if he was satisfied that the figures represent the level of inclusion in the registers and level of reassessment that he anticipated when he signed off the post Winterbourne View programme of action in December. The Minister replied that if we use the strictest definition of the people to be reviewed, then we have covered the intended group. However, he said that possibly this should be extended and more people should be having their care reviewed.

5.7 Ivan continued with the slides, updating the group on the next steps for NHS England to assure quality, including a wider sampling exercise to test the quality of reviews and doing a deep dive regarding former Winterbourne View patients. The Minister asked to know urgently the current settings of the people who were in Winterbourne View, and whether their current setting equates to what their review concludes they should be, and if there is a mismatch what are commissioners doing to address the matter. Viv said that Respond should be linked in so that this vulnerable group of people have access to any further support that they might need, as DH were funding them to provide support to ex-Winterbourne View residents.

ACTION 8: Chris, Alan and Ivan to update MS(CS) about the former Winterbourne View patients and if their current setting is the right one for them.

ACTION 9: Involve Respond in results from deep dive for former Winterbourne View residents.

5.8 Viv asked Ivan if the two Fora will be included in the sample exercise and could help check a small number of reviews. Ivan said people with learning disabilities and family carers should be involved as the team is being set up, to give a strong element of external reassurance, although the deep dive will take a number of months. Chris Bull said it was likely that some people may be stuck in a “transitional” setting.

5.9 Craig said that it was important that the reviews were conducted correctly and also that people were given sufficient time to make their own choices. He said that they should have an advocate if they need one so that people's rights are not taken away. He said that there should be extra support for people who have been abused. Craig added that some people need more time to move into different types of care, but others need to be moved more quickly if the care is wrong.

5.10 The Minister told the Board that Mencap had raised a £10m bond to provide specialised housing, but they have not had enough take-up from commissioners. Viv said that single person properties are hard to find. It was agreed to have a specific item on housing on the agenda for the next meeting which shows further analysis and perhaps involve the Department of Communities and Local Government (DCLG).



ACTION 10: Include housing on the agenda at the next Board meeting, and to write to DCLG.

5.11 Alick Bush noted that the terminology used should be “people whose behaviour is challenging / can challenge” and not “people with challenging behaviour”.

ACTION 11: Amend reports to reflect terminology should be “people whose behaviour is challenging / can challenge” and not “people with challenging behaviour”.

5.12 Craig pointed out that the pictures do not match with the words in the NHS England slides. He said this should be changed so it is in easy read format. The Board agreed that papers should be in proper easy read format with relevant pictures.

ACTION 12: All Board members to note easy read format for papers they are preparing for future meetings. DH to circulate guidance on easy read.

		Update from Joint Improvement Programme
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5.13 Chris Bull talked through the slides (paper LDPB(13)20). The Joint Improvement team will receive a lot of information from the Local Authority stocktake. He said there will be a piece of work done to understand trends in the short-term. Chris also said that the Joint Improvement Board talked a lot about children and definitions at their last meeting, and there is a piece of work to follow on this.

5.14 The Minister noted that he had heard anecdotally that A&T units are still taking people in, which was echoed by Vicki Raphael, and he said that if this transformation does not work, he will have to be more prescriptive. Jon Rouse requested that the length of stay in A&T units must be measured. Zawar Patel offered to share the questions that have been developed for the census with the Board for their comments. This will include length of stay.

ACTION 13: Census questions to be circulated to the Board after the meeting for their comments. Responses were to be received by Wednesday 10th July.

5.15 Questions were raised about whether the number of A&T units is known. Alan said there are 168 A&T units in England, but that does not show how many different locations there are which would be much more (around 500). Alan agreed to share a piece of work done by Eric Emerson on the inspection of services after Winterbourne View.

ACTION 14: Alan Rosenbach to circulate Eric Emerson's work on inspection of services after Winterbourne View.



Update from Care Quality Commission (CQC)

5.16 Alan Rosenbach discussed the changes that CQC are making to registration for new services starting with learning disability providers (paper LDPB(13)21). Alan said that it will then be retrofitted to existing providers and also linked in with inspections. He said the CQC receives around 4 to 5 applications per month for learning disability facilities and that they are warning providers who may be applying to set up A&T services that they must fit with the model of care.

5.17 The Minister informed the Board that a consultation launched on 4 July to pave the way for prosecutions of providers who fail to meet standards, because it will remove the rule that CQC has to serve notice before prosecuting in certain instances.

5.18 Alan said that experts by experience were taking part in inspections, and that they could also be involved in the registration process. Craig Hart said the National Forum could help, which was welcomed by Viv Cooper. Ciara Lawrence explained that at Mencap, during the recruitment process all staff were interviewed by a person with learning disabilities. She said that as Mencap is an expert in this kind of training, then it could help in setting up the process at CQC.

ACTION 15: CQC to work up a proposal on how they plan to make more use of experts by experience in the new registration process and will circulate to the Board.

ACTION 16: CQC to follow up with Mencap about training people with learning disabilities.


5.19 The Minister asked what proportion of inspections include experts by experience. Alan answered that for learning disability A&T services, experts by experience are included. Craig was concerned that CQC

inspections do not regulate personal assistants, but Alan said that CQC do regulate services where staff employed by a care provider visit a patient in their own home. Karen Flood reported that it was still a worry that people who have been trained as experts by experience are not being used and that money is being wasted on retraining people because of the contracting processes CQC use.

	Update from Health Education England (HEE)
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5.20 Chris Welsh introduced the slides covering the role of HEE in the new health and care system. He said it was the first time a single organisation has been empowered to look at the education and training for the whole healthcare workforce (e.g. pharmacists), and not just people paid by the NHS. Chris Welsh said it is a small central organisation with 13 Local Education and Training Boards – and that contact details could be found on the back page of the slide pack (LDPB (13)23).

ACTION 17: It was agreed that HEE should be an agenda item at a future Board meeting.

	<p>6. Overview of all Programme Workstrands</p> <p>What is happening on all the other actions people said they would do after Winterbourne View?</p>
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6.1 Frances introduced the workstrand summary paper LDPB(13)24 and noted that the Fora had pointed out that the traffic light statuses (all amber/green or amber) mostly tracked processes or outputs, rather than outcomes for people with learning disabilities and their families.

ACTION 18: Add another rating to monitor outcomes which the Fora will be involved in developing with DH.



Workstrand 1: Right Care, Right Place

6.2 John Crook highlighted the key points on Workstrand 1 (Right care, right place) which was rated amber overall, due to the previously discussed issues over the lack of confirmation of quality of the reviews and that there had been some delays on service specifications for children.



Workstrand 2: Regulation, Inspection & Corporate Accountability

6.3 Mark Bennett updated the Board on Workstrand 2 (Regulation, Inspection and Corporate Accountability) rated amber, including the consultations from CQC (*A New Start* published 17th June) and Department of Health (corporate accountability published on 4th July) which he encouraged Board members to take part in. Vicki Raphael pointed out that meeting minimum standards does not make it a good service. Alan agreed by saying that satisfactory is not good enough and the new rating systems will enable trends to be monitored to see if the service is improving or not.



Workstrand 3: Good Practice, Standards & Advocacy

6.4 Pam Nixon covered Workstrand 3 (Good Practice, Standards and Advocacy) which was rated amber/green due to delays with the Quality Performance Mark and Code of Practice. This was due to Action 4 Advocacy closed at the end of May who were due to carry out this piece of work. Viv and Vicki said they had concerns around advocacy generally because even if the Winterbourne View actions were on track,

advocacy provision overall is at risk. They said this is partly due to benefits reform which can make it harder to access good advocacy. Chris Bull said that advocacy will be added to the next Joint Improvement Programme Board agenda for discussion.

ACTION 19: Include advocacy as an item on the next Joint Improvement Programme Board meeting.



Workstrand 4: Information & Data

6.5 Zawar Patel updated the Board on Workstrand 4 (Information and Data) which was rated amber overall. Zawar highlighted the work on the self-assessment framework (SAF), census (see action 13) and minimum data set. Vicki asked if Board members can pass the SAF onto others.

ACTION 20: Sam and Zawar to send SAF to Vicki as soon as possible.




Workstrand 5: Medication, Positive Behaviour Support and Physical Intervention

6.6 Pam Nixon talked about Workstrand 5 (Medication, Positive Behaviour Support and Physical Intervention) being a tricky area to get agreement from all parties on and hence the amber/green risk rating. The Minister commented that the freedom of information (FOI) request from Mind showed widespread variation of restraint practices and that it could be an idea to publish systematic data as this might drive better practice.




Workstrand 6: Workforce

6.7 John Crook went over Workstrand 6 (Workforce) rated amber/green as there had been a delay in producing the guidance produced by the Royal College of Psychiatrists on the different types of inpatient services due to differing views over the content. Bruce Calderwood said that it highlighted the scale of the challenge in engaging that part of the workforce who do not always share the approach outlined in *Transforming Care*.

	Workstrand 7: Children and Transition
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6.8 The update on Workstrand 7 (Children and Transition) was reported by Anne Spence and was rated amber/green. She added that the Winterbourne View programme had a perception of being focused on adults and not children, so communications need to be improved to change that perception.


	Communications
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6.9 Amy Key then updated the group on the communications strategy as she has been working with the Joint Improvement Programme on a short/medium term action plan to raise awareness. The Minister wanted to reinforce the message and suggested he writes to commissioners asking them to stop referring people inappropriately to A&T units and reminding them about the Census.

ACTION 21: MS(CS) to raise with NHS England writing to commissioners asking them to stop referring people inappropriately to A&T units and a reminder about the Census.

6.10 Vicki asked why Scotland has a new learning disability strategy but England does not. Andrea Pope-Smith said she would support this.

ACTION 22: Submission to be sent to MS(CS) giving information on the Scottish learning disability policy and for a paper on how we look at wider strategic issues to be discussed at the next Learning Disability Programme Board meeting.

 <p>Department for Work & Pensions</p>	<p>7. Other Government Department Reports</p> <p>Department for Work and Pensions (DWP)</p>
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7.1 John Skinner said he wished that he could give more information to share with the Board, but that details were not readily available following the spending review. He said that DWP will inform the group when a decision is made about short-term changes to the Access to Work scheme and how this supports disabled people. John said that the programmes had been reasonably successful but there was still a 30% gap between the number of disabled people getting back to work compared to non-disabled people so DWP is aware that there is more to do. See paper LDPB(13)25 for more information.

ACTION 23: DWP to inform Board members about changes to the Access to Work scheme and how this supports disabled people when information is available.

ACTION 24: A representative from the LDPB should be involved in the DWP Stakeholder group – DWP to action.

7.2 Andrea noted that the current apprenticeship scheme has an entry requirement of Level 2 for maths and English which meant it was very hard for people with learning disabilities to get onto the scheme even though they could make good employees. John agreed that DWP needed to do more to support employers in how to take on more

disabled people. He said that there was a conference taking place in August with over 500 employers to share best practice in employing more disabled people.

7.3 Craig said that people were very worried about the benefit changes and they need to get the right support, but that this was not easy to find now that advocacy services were closing. John Skinner said that Universal Credit should reduce problems and help people who do seasonal work or work for only a few hours a week.

 <p>Department for Business Innovation & Skills</p>	<p>Department for Business, Innovation and Skills (BIS)</p>
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7.3 Howard Bines gave a verbal update from BIS. He said a pre-apprenticeship programme will start running in September for 16-24 year olds called “Traineeships” and although it is a mainstream programme, people with learning disabilities should be able to access it. Howard said that BIS are hearing that apprenticeships need to be made more accessible and that the Skills Minister was meeting with the Special Adviser for the Minister for Disabled People about accessible apprenticeships.

7.4 Howard said that there is progress being made giving a range of support for people with learning disabilities who go to university, also micro-businesses, mentors and assistive technology. Andrea said she was glad to hear of the shift, but that a bespoke apprenticeship scheme should be set up. She said they could set up a pilot in the Dudley area.

ACTION 25: Howard and Andrea to link up outside the meeting to discuss a pilot of a bespoke apprenticeship scheme for people with learning disabilities.

7.5 Ciara recounted her personal story of how she was not made aware of disability advisors at her local job centre for a long period. She

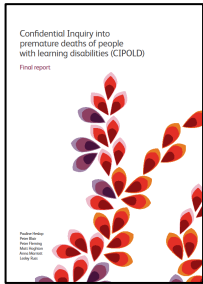
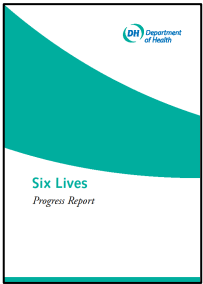
said how application forms can be very difficult without support, but when she accessed this support, it helped her gain employment with Mencap. John Skinner agreed that it was important that people are informed about disability advisors automatically when they visit job centres.

 Department for Education	Department for Education (DfE)
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7.6 Helen Nix updated the Board on the Children and Families Bill which entered the House of Lords on 2 July and continues to be on track. The Bill contains clauses on integrated working and joint commissioning, which is being reflected in a chapter on the SEN (Special Educational Needs) Code of Practice. Joint commissioning offers areas an opportunity to better design care pathways which make sense to children, young people and their families as well as professionals.

7.7 Helen said that Ofsted have committed to delivering joint inspections but have had to pause to build up their capacity to deliver them with CQC. Helen also commented on residential care guidance being covered by her colleague, Sarah Carter, which has already had helpful comments from DH colleagues, and will also be shared with Christine Lenehan. DfE are willing to share a draft with the Board if they wish to see it. DfE also undertook to give an update on data at the next Board.

ACTION 26: It was agreed there should be an agenda item at the next Board meeting about the SEN reforms and how they complement the work of the Board, with a particular reference to integrated care pathways.

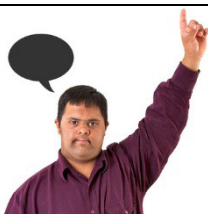
 	<h2>8. Other Department of Health (DH) Activity</h2>
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8.1 Frances informed the group about the review of the Autism Strategy to identify progress and areas of good practice and to consider next steps in its implementation. Frances encouraged Board members to submit their views through an online survey for self-advocates and family carers which closes on 9 August.

ACTION 27: Board members to contribute comments to Autism Strategy review and to draw attention to the survey available at this link:

<http://www.surveymonkey.com/s/AutismStrategyReview>
before 9 August.

8.2 Frances said that DH was about to publish two documents on 12 July: the response to the Confidential Inquiry and the second “Six Lives” progress report. Further details would be forwarded in due course.

	<h2>9. Any Other Business</h2> <p>Anything else?</p>
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9.1 Board members were asked to fill out the feedback forms.

9.2 Jon Rouse thanked all members for their contributions.

9.3 Next meeting is on 19 November 2013 at 1.30pm, Boardroom, Richmond House.