

CLLSA Cambridge Conference 10 March 2017

Key Findings and Action Points

Key findings

1. The conference set a very high benchmark for participant satisfaction, higher than any of the four 2016 conferences, which already scored highly. See Table 3. Appendix 1.
2. Once again, the calibre of the keynote speaker was the major attraction, with 27 participants volunteering that George Follows' presentation was the aspect 'most liked'. One attendee wrote: *'Presentation by George Follows – just what I want from a clinician. Inclusive, personable and superb handling of questions'*. 'Presentations' scored 96% satisfaction and were the most highly rated aspect of the conference. See Table 3. Appendix 1.
3. Presentations by our three patients / carers were well received. We recommend more than one presentation by members to give a more rounded experience. We do not distinguish between the keynote presentation and short presentations by patients and carers on our feedback form: they are assessed together under 'presentations'. Three participants singled out the presentations by patients / carers as the aspect they 'most liked'. See Tables 3. and 4. Appendix 1.
4. The opportunity to meet and talk to fellow patients and carers was confirmed as much appreciated by participants. Nineteen volunteered that this was the aspect they 'most liked'. See Table 4. Appendix 1.
5. The disappointing rate of return of completed feedback forms, just 44% for the four conferences in 2016, was overturned with a 72% return at Cambridge in 2017. This gives credibility to the findings quoted in this report. See Table 2. Appendix 1.
6. We were gratified that ten participants cited 'the group discussions' as the aspect 'most liked'. (Overall satisfaction 89%) Tables 3. And 4. Appendix 1. Credit goes to our ten volunteer group facilitators for this pleasing result. They enabled us to keep groups small and ensured more focus to discussion.

This report summarizes participants' deliberations on

- Their unanswered questions - Appendix 2.
- Tips for coping with CLL - Appendix 3.
- How they might support CLLSA - Appendix 4.
- Contributing to CLLSA funds and fundraising - Appendix 5.

It is vital for CLLSA to follow up participants' feedback with action. See below.

Although we gained valuable insights on perceptions and raised members' potential engagement with CLLSA from the group discussions, we advise future conferences to devise a less paper-driven exercise than at Cambridge.

7. Composition of attendees was: 60% first timers; 40% returners
69% CLL patients (of whom 60% WW)
27% Carers
3% Others

See Table 1. Appendix 1. for actual figures and sources of this information.

Action Points

The measure of a responsive association is in the action it takes following members' feedback. The following questions and proposed actions are put to the CLLSA Board for their consideration. The list is daunting. The Membership Committee cannot undertake it all without support from other Trustees. We have indicated HP for high priority, either where the proposal is relatively easy to execute or where action is pressing.

1. **Membership fee and Conference fee** See Appendix 5. HP
Qu. 1. Is the Cambridge feedback sufficient indication of members' views?
Qu. 2. Can the Board now make a recommendation for a membership fee and a conference fee?
2. **Launching of local support groups** See Appendix 4.
Qu. 3. Should we measure availability of potential volunteers for launching local support groups at all our conferences in 2017? HP
Qu. 4. What support and encouragement can Trustees offer to potential member volunteers? Who will take this on?
3. **Telling your CLL story** See Appendix 4.
Qu. 5. Should we try to get more potential CLL story tellers at other 2017 conferences? HP
Qu. 6. Would Trustees advocate a sponsored CLLSA publication of CLL patient and carer stories, to be available for sale? Who would edit it?
Note: Our list of potential volunteers is a source for conference presentations.
4. **Becoming an ambassador** See Appendix 4.
We have a list of potential volunteers and their CLL hospital, with a view to their spreading the word about CLLSA to more patients and carers.
Qu. 7. Would trustees support testing for potential CLLSA ambassadors at all forthcoming CLLSA conferences in 2017? HP
Qu. 8. How do Trustees propose to use these ambassadors?
5. **Group discussion facilitators** See Appendix 4.
We have started a list of potential group discussion facilitators.
Qu. 9. Would trustees support testing for potential group discussion facilitators at all forthcoming CLLSA conferences in 2017? HP
6. **Members' unanswered questions** See Appendix 2.
These are specific to attendees at Cambridge. A prompt response is desirable. This could be achieved through a written response devised by an ad hoc committee of trustees, advised by a clinician / CNS. The response could be:
 - emailed to attendees
 - put on the CLLSA websiteQu. 10. Are any Trustees able to help with this? HP
7. **Members' tips for coping with CLL** See Appendix 2.
Qu. 11. Do Trustees support putting these on the website? If so, how?
Do we endorse use of complementary medicine/ therapy?
8. **A short report on the Cambridge conference to all attendees.** HP
We recommend emailing all attendees a one- or two-sided report on conference findings and proposed follow-up actions in the next fortnight. OJ is willing to draft such a report. It will act as a holding device for those actions which will take us longer to implement. The report can also be on our website.
Qu. 12. Does OJ have Trustees' support for this?

Table 1. Composition of attendees

Attendees	82	
No show	5	6%*
First timers	33	60%
Returners	22	40%
Trustees	5	DI, CT, RB, AC, OJ
Coordinator	1	
Clinicians	2	George Follows - speaker, and Barts CNS
Charities	1	Lymphomas Org.
CLL patients	43	69%
Carers	17	27%
Others	2	3%

* 6% compares with 11% overall in 2016 from 4 conferences, which ranged 7% -14% no show.

Note: 60% CLL patients WW, data from discussion groups. Ist timers/ returners from feedback forms

Table 2. Rate of conference feedback returns

82 attendees	59	72%*
75 attendees	59	79% discounting trustees, speaker and coordinator

*72% compares with 44% return from 4 conferences of 2016, which ranged 38%-52% return.

Table 3. Satisfaction levels for each of the 5 aspects measured

	All respondents					%*	%1st time	% return	% 2016 confnrces
	Fair	Avrge	Good	Excelnt	Total				
Location, Facilities	0	1	14	44	59	95	96	94	91
Presentations	0	1	11	47	59	96	95	98	89
Event materials	0	0	26	33	59	91	93	89	88
Advert/registration	1	1	23	32	57	90	89	92	87
Group discussions	0	3	25	27	55	89	89	89	83

* % calculated by multiplying 'fair' by 4, 'average' by 6, 'good' by 8, 'excellent' by 10 and dividing the total by the number of respondents for that aspect, to give an average, which was multiplied by 10. % awarded also shown for first time attenders and for returners, and for all four 2016 conferences. No instances of 'not so good'.

Table 4. Most liked - observations volunteered by attendees

George Follows presentation	27
Patient /carer presentations	3
'Presentations'	2
Meeting /talking other patients /carers	19
Group discussions	10
Information learned, incl. info pack	4
Learning about new developments	2

Note: All 59 respondents completed this section. Some gave more than one thing 'most liked'.

Table 5. Least liked - observations volunteered by attendees

Nothing; N.A. ; all good	18
Thumping/tapping of mike by Olga!	5
Difficult to hear	3

Note: 33 attendees responded. 7 individual comments, not recorded here, logged on database.

Members' unanswered questions

Appendix 2

Discussion groups were invited to list those questions about CLL, which members in the group could not answer. We informed members that we would do our best to answer these, but could not guarantee to provide an answer. Questions unanswered at the conference are listed below, unedited.

Some of these are best answered by the CLL clinic of the patient.

Others might be answered by a small ad hoc working party of trustees and a CNS/haematologist. This could then be written up for email to conference attendees and put on the CLLSA website.

There are a few themes which might be covered in 2017 CLLSA conferences, viz: carers' role (5,6,9); managing symptoms and side effects (1, 7, 11, 18, 19).

1. Can I carry on a normal life? i.e. travelling on a busy tube, teaching small children (infections?)
2. What are NEABS?
3. How easy is it to get on trials? Is this the best option to access the latest drug?
4. Why was the info supplied on the after clinic letters cancelled?
5. How do you stop compassion fatigue amongst family and friends?
6. Advice for the carer and family to deal with CLL.
7. Weight loss (sic)
8. Where to find relevant information about the various treatments?
9. Help to be able to talk to people without them feeling sorry for me.
10. Any of the following worth doing: Vitamin C Therapy; Vitamin D therapy; Beta Glucan therapy; removal of mercury fillings? And high dosage protocol?
11. Keeping infections at bay.
12. How to extend the message to all CLL patients?
13. How do you decide it is time for treatment?
14. Does Ibrutinib always cause internal bleeding?
15. Are there any medicines while you are on watch and wait, and at stage A?
16. What are long-term effects of Ibrutinib? How latent are they?
17. Is CLL a new type of leukaemia? When did it first appear?
18. How do you control side effects?
19. IgG deficiency causes. Infections, colds, pneumonia etc (40% of all patients die of pneumonia.) What treatment options are available to counter this, besides transfusions?
20. How many people dying from pneumonia but with CLL would have CLL given as a reason for death?
21. Could the CLLSA website list of consultants with a particular interest in CLL be reinstated? It was much liked.
22. Is there a higher incidence of skin cancer amongst CLL patients?
23. How soon can you ask for specialist tests to see if you have 17p deletions etc, if you are still on watch and wait?
24. Is there a possibility of dose reduction on Ibrutinib?
25. What about the replacement of Ibrutinib with Venetoclax?
26. Effectiveness of EHIC insurance for EU travel with CLL?
27. Better to be ignorant or told you have CLL, (if no treatment recommended)?
28. Did CLLSA investigate the extent of investigations members have had e.g. bone marrow, FISH test etc?

These are the tips put forward by the 10 discussion groups at the conference. It is proposed that they are edited and put in the next CLL newsletter.

A preamble to the article might read:

CLL patients and carers at the Cambridge CLL conference in March 2017 gave the following tips, which had helped them to cope with CLL. It is your decision whether you choose to try them for yourself.

Are there any tips listed below which the Board are not happy to endorse?

1. Reach out for support: Macmillan, friends, family, local support groups
2. Don't be dominated by CLL
3. Always take someone with you to your GP or consultant, especially when receiving a diagnosis.
4. If you suspect you have any symptom (e.g. shingles, pneumonia), go to your GP immediately
5. Keep fit; join a walking group
6. Gain knowledge to understand your CLL
7. Be positive, but have regular consultations/blood tests.
8. Do not be afraid to ask for a second opinion
9. Take simple precautions, e.g. wiping surfaces, a face mask
10. Come to terms realistically with your condition
11. It's important to structure daily/weekly life with positive actions
12. The carer's position is key; needs all the support
13. You have to be in control
14. Turmeric and green tea
15. Never stop thinking positively
16. Keep busy, and keep CLL out of your mind
17. Use Maggie's Centres
18. Complementary therapies can be helpful: acupuncture, tai chi, mindfulness
19. If having infusions, take vitamin D and green tea
20. If having chemo, drink lots, before and on day of treatment and on day after
21. Always take anti-biotica with you on holiday
22. Be kind to yourself! e.g. book a course of facials. I consider them medicinal. I feel good and extremely relaxed afterwards.
23. Pace yourself – give in to fatigue/sleep when you need to, but have fun too.

Table 1. Figures

	not likely	not sure	maybe	quite possibly	probably	sample
Tell your CLL story	16	10	16	6	11	59
Become ambassador	21	15	12	8	5	61
Discussion gp. facilitator	33	5	12	4	7	61
Help run regional group	24	11	10	10	6	61

Table 2. Percentages

	not likely	not sure	maybe	quite possibly	probably	sample
Tell your CLL story	27%	17%	27%	10%	19%	100%
Become ambassador	34%	25%	20%	13%	8%	100%
Discussion gp. facilitator	54%	8%	20%	7%	11%	100%
Help run regional group	39%	18%	16%	16%	10%	100%

Summary of findings

1. This sample gives us a snapshot of potential interest in volunteering as of March 2017 amongst Cambridge conference attendees, who are about 3.5% of CLLSA membership.

It shows a small core of members who are disposed to active involvement in support of CLLSA. This is promising. They will need encouragement and support to make their volunteering effective and rewarding. Many Cambridge participants were attending their first conference and were not ready to get involved further. Some do not want an active role.
2. 'Telling your CLL story' had the best response. This could be a good source for presentations at conferences or, possibly, a publication by the CLLSA, for which we might get sponsorship.
3. 'Helping us run a regional support group near you' had a good response. We hold data on potential volunteers' names and their CLL clinic/hospital. There are clusters of interest, notably at Addenbrookes and for the London group, possibly hosted by Barts.
4. 'Becoming an ambassador for the CLLSA' scored lower, in part because some members felt there was already good awareness of CLLSA in their clinic/hospital. The 'lobbying' aspect was not associated with being an ambassador. Interest in lobbying should have been measured separately.
5. Our pool of potential discussion group facilitators is larger than the figures above suggest. Six of the Cambridge facilitators did not complete a form but have declared a willingness to facilitate again.

Fundraising

Specify a need for donations.

Ideas and experience put forward, some with named contacts, were:

1. **Sales**

- 2nd hand sales
- craft sales
- bake sales
- boot sales
- CLLSA items : T shirts, mugs etc

2. **Fun activities**

- quiz night
- race night
- family fun day
- coffee mornings
- fun night walk
- sponsored walk
- dress up in purple day

3. **Charity boxes**

- local shops
- Waitrose

4. **Company sponsorships**

- Linked to a specific task / event

5. **A fundraising day for CLLSA**

6. **On line conferences**

Cambridge CLLSA Conference Programme

Friday 10 March 2017
Cambridge City Hotel

- 10.00 Registration
- 10.30 Introduction and Welcome by David Innes, CLLSA chair
- 11.00 CLL: The disease and its treatment in 2017 and beyond

Dr George Follows, Clinical Lead, Lymphoma, CLL Service
Cambridge University Hospitals NHS Foundation Trust
Addenbrookes Hospital
- 12.30 Lunch
- 13.30 Facilitated small group discussions
An opportunity to share tips for coping with CLL and
learn how you can support the CLL Support Association
- 14.45 Tea/Coffee break
- 15.00 Presentations by three volunteer patient/carer speakers
about their experience of CLL

Molly Fletcher
Olga Janssen
Andrea Cockburn
- 15.45 Summing up and conclusion of the day by David Innes
- 16.00 Close of meeting

