

Commentary on what worked well

- A good range of well-received, well-pitched and timed clinical presentations

Satisfaction ratings for the presentations were very high at 94%. Forty-seven of 68 participants volunteered that this was the aspect of the Conference they “most liked”. (Appendix 2). We benefitted from the connections of Samir Agrawal, CLLSA trustee and haematology consultant at Barts, who engaged two of his colleagues to join him in giving presentations on well-chosen topics to suit a lay CLL audience. These were 60, 40 and 20 minutes long, including an opportunity for questions from the audience. Group activities and breaks interspersed the presentations so as to lighten the demands of continuous concentrated listening, which members have found taxing at other CLLSA conferences.

Consultant Piers Patten opened with a presentation on the latest CLL treatments available on the NHS. He outlined the broad range of CLL patients: those, about a third, whose disease is indolent and who never need treatment; a third whose disease is initially indolent but progresses to require treatment: a third whose disease is aggressive and who need immediate treatment. He explained initial assessment and the tests available for making a precise diagnosis and determining the best treatment. He then explained the range of treatments available on the NHS and trials. There are lots of options. The combination of drugs is the issue in current clinical trials. Members found Piers Patten’s presentation very accessible and had lots of questions for him.

The second presentation was given by Samir Agrawal on the Remote Care Programme at Barts, now in operation for two years and recently evaluated in a patient experience survey. Suitable patients, who have a face-to-face facility on their mobile phone, opt into the system. They complete a paper questionnaire on their quality of life, and send in a blood test, which can be done at their GP surgery. They can access the results on line and have a video-assisted follow-up conversation with their consultant. Patients like the system, which they have found easy to use, convenient, patient-centred and empowering. Samir Agrawal, assisted by patient Pauline Stow’s case study, made a powerful case for the Remote Care Programme to be adopted more widely. A show of hands from the 100 members of the audience at the Conference indicated a large majority to be enthusiastically in favour of the scheme being adopted in their clinics.

After lunch John Gribben gave a presentation on CAR-T cell therapy. This new therapy is still in development but already getting the clinical community very excited. The presentation was well illustrated with moving graphics, which made it readily understandable to a lay audience. The therapy is a system for supercharging the patient’s immune system. Immune cells – T cells – are taken from the patient’s blood and re-engineered in the laboratory to produce chimeric antigen receptors (CARs). These re-engineered immune cells are put back in the patient’s blood, where they target proteins on the cancer cell’s surface and multiply to attack the cancer.

We are very pleased that all three presentations from Barts were put on the CLLSA website within 24 hours of the Conference by our volunteer, Andy Diss. They can be found on: <https://www.cllsupport.org.uk/article/cllsa-london-barts-conference-nov-2017>

Our two CLL stories gave a patient’s (Surjeet Soin’s) and a carer’s (Gail Wiegman’s) experience. Surjeet Soin has now opened a just giving account for his winter walk early in January in aid of CLLSA <https://www.justgiving.com/fundraising/surjeet-soin8>

- Use of the Conference for determining and taking forward patient priorities

When Samir Agrawal first spoke at the Barts 2015 Conference about the inception of the Barts Remote Care Programme, some conference attendees dismissed its relevance to them: “*too local to Barts*”. Two years on and with the endorsement of 58 Barts’ patients, whose quotes in support of the scheme were given on a handout at the Conference, Conference attendees were won over. A show of hands indicated that a large majority would like to see the system adopted at their clinics. One enterprising CLLSA member spoke to the Bloodwise and Leukaemia CARE reps as well as to CLLSA trustees in attendance, proposing that they collectively fund the launching of the scheme in other hospitals. This resulted in an exploratory conversation between the Chief Executive of Bloodwise and Barts immediately after the Conference and email exchanges between CLLSA trustees who have offered their support to Samir Agrawal for extending the scheme outside Barts.

Our “Three Wishes” consultation exercise, analysed in Appendix 4 of this report, yielded a clear set of priorities for CLLSA members. The Board of Trustees discussed the key findings listed, on 27 November, and made a series of recommendations for taking action in 2018 to meet members’ wishes. These are given at the end of Appendix 4.

- Good opportunities for informal networking and sharing of CLL experience

As usual, we received many unsolicited compliments about the opportunities for interaction with CLL patients, carers, healthcare professionals and charity reps. For many patients, CLLSA conferences are their first and only opportunity to meet other CLL patients. We recognize the importance of this and allocate a full hour for lunch and ample time for small discussion groups to facilitate informal networking and sharing of CLL experience. Thirty-two respondents, out of the 68 returns we received, volunteered that this was the aspect of the Conference they most liked. (Appendix 2.) Observations made include: “*being in a supportive group*”; “*meeting others with CLL, talking about problems etc.*” Two clinical nurse specialists (CNSs) and two consultants joined the group discussions. They were a reliable source of information, appreciated for their contributions to group discussions.

- High level of attendee satisfaction with the conference materials

Strikingly, satisfaction with the Conference Materials at Barts has risen from 83% in 2015 to 93% in 2017 (Appendix 2). Trustees have worked hard to augment conference materials, colour-coding them for ease of reference. The programme now gives mini biographies of guest speakers to whet appetites and give attendees an insight into the expertise of presenters (Appendix 5). We also specify topics and provide simple worksheets for discussion groups to capture members’ views. Two other innovations have been the jargon buster and the more explicit sheet of advice on good CLL websites and online communities. The jargon buster explains the most common NHS acronyms, which can be difficult for patients to interpret, but also the various job titles and roles of members of the multi-disciplinary team (MDT), who care for patients, often unknown to them.

This year we have put conference materials in a branded CLLSA cloth shopping-bag. We hope to encourage members to help us in the marketing of CLLSA by using the bag in clinic and out and about to trigger conversations about our Association and its benefits for patients and carers. Our current membership is just over 2,000. There are about 25,000 CLL patients nationwide. We would like to attract more members.

- Improvements in response to feedback from the 2015 Barts' Conference

Many attendees at the 2015 Barts Conference, commented on the theatre-style seating, which they disliked. We changed this to more companionable, round-table, cabaret-style for 2017, which was appreciated. Feedback included: "*Sitting at tables in the round was very friendly.*" Another commented on "*the camaraderie*", a feature of the Conference which cabaret-style seating promotes.

We had also received feedback about the inadequate sound system in 2015. This time we went to great lengths to ensure that the sound system was optimal in all areas of the Great Hall and received only two adverse comments. (Appendix 2.)

The long trek to the toilets down a winding corridor in the basement of the Great Hall, which many had complained about in 2015, was partly alleviated by the advice of alternative, more accessible toilets in a neighbouring building in 2017.

Commentary on what could have been better

- The services of Barts Great Hall

Despite CLLSA conference organisers' best efforts, we were let down by inadequacies in the local service at Barts.

2015 Conference attendees had commented on the poor signage for the Great Hall. We were advised in 2017 to provide signage in advance, which the Barts staff would put up for us in preparation on the day. It was not there ready, and we had to improvise.

We had experienced difficulties locating our couriered conference materials in 2015 and found them down a back staircase. Anxious to avoid this in 2017, we sought the advice of the Administrator of the Great Hall, who advised us to address the materials personally to her at the Great Hall and they would be put out ready for us. However, unknown to us, the Great Hall is kept locked and our couriers were unable to deliver when they came the day before as planned. Moreover, the telephone was set to the answer-machine at Barts when we checked at 9a.m. on the day and there was no one in authority at the Hall til 10 a.m. The materials eventually arrived at 10 a.m., once we had assured the couriers of access. There were two unfortunate consequences. Trustees and volunteers were rushed to set up and unable to meet and greet members as they arrived. The careful planning to allocate members to tables with others who lived in their area, got overlooked by some. The lower score than usual awarded for registration reflects these shortcomings. (Appendix 2)

For attendees, the aspect they liked least about the Conference was the cold. We received 39 comments on this from 57 respondents. (Appendix 2.) We had checked in advance with the Administrator about how we could adjust the temperature, but were informed that this is centrally managed and outside her and our control.

Barts requires us to use the services of the firm they specify for audio-visual installation. They did an excellent job. A disadvantage for us is that we were not allowed to bring our cameraman to video presentations and so had to forgo putting videos of presentations on our website, to refresh memories and make the presentations publically available to all.

We like Barts and the splendour of the Great Hall, its historic significance and central location, but there are handicaps for hiring it as a conference venue.

Report compiled by Olga Janssen
CLLSA trustee, December 2017.

Composition of Participants at London Conference 2017

Attendees:

Total	100
Cancellations/ no show	10 (9%)
Waiting list, not accommodated	0
First time member attendees	28 (43%)
Returning member attendees	37 (57%)
(Unknown status members	<u>4</u>)
Total members	69*

**Information from feedback forms. Some members did not complete a feedback form. For comparison, this year first timers were: Cambridge 60%; Liverpool 53%; Leicester 28% Oxford 69%*

Trustees: CT; AC; SA; OJ; RH; GW	6
Healthcare Professionals:	
Clinicians: PP; JG; SA	3
Nurse specialists: TE; LF	2
Charity Reps: Leukaemia CARE: NY; DM	3
Bloodwise: LR	1

Discussion Group composition:

CLL patients	48 (67%)
(Of whom on active observation/ watch and wait: 38 (79%))	
Supporters/ carers	21 (29%)
Health care professionals	3 (4%)
Total	72

NB. Facilitators are included in these figures. Two groups did not provide info. For comparison, this year CLL patients were: Leicester 61% (of whom ww. 40%); Liverpool 66% (of whom ww. 48%); Cambridge 69% (of whom ww. 60%); Oxford 65% (of whom ww.45%)

Note on Cancellation/no show rate

Cancellation rates in 2017 averaged 10.6%:

Cambridge	6%
Liverpool	8%
Leicester	15%
Oxford	15%
London	9%

Cancellation rates in 2016 averaged 10.25%:

Glasgow	7%
Southampton	9%
Nottingham	11%
London	14%

This suggests that we can confidently overbook by 6% in future.

Analysis of returned feedback forms from participants

Satisfaction levels for each of the 5 aspects measured at London, Nov. 2017

	Not so good	Fair	All respondents			Total respnd	%*	% 1 st time attend	% 2 nd plus attend	% 2017 all 5 conferences
			Average	Good	Excellent					
Advert, register	2	2	2	31	30	67	85%	81%	89%	90%
Location, facilities	3	2	4	36	24	69	82%	84%	80%	92%
Event materials	1	0	0	29	39	67	93%	91%	90%	92%
Group discussions	1	0	3	30	33	67	88%	88%	88%	88%
Presentations	0	1	1	17	50	69	94%	93%	95%	93%

Notes

- * Percentages are calculated by multiplying “not so good” by 2, “fair” by 4, “average” by 6, “good” by 8 and “excellent” by 10. The sum is divided by the number of respondents, to give an average out of a maximum possible score of 10. This figure is multiplied by 10 to give a percentage score. Figures are rounded to full % point.
 A score of 80% would indicate overall: “good”.
 A score of 100% would indicate all respondents rated it “excellent”.
- There were 69 completed feedback forms, from a total of 91 attendees (6 trustees, the CLL coordinator and visiting speakers excluded), i.e. 76% return. We aim for a minimum return of 60% to be confident of findings.
- Of the 69 completed feedback forms, 4 did not indicate whether they were first time attendees. Of the remaining 65 returns, 28 were from first-time conference attendees, i.e. 43%. This compares with Oxford (September 2017) 69%; Leicester (July 2017) 28%; Liverpool (May 2017) 53%, and Cambridge (March 2017) 60%.
- CLLSA last had a conference at Barts in 2015. Comparative satisfaction figures for the two conferences are:

	2015	2017	change
Advertising and registration	88%	85%	- 3%
Location, facilities	85%	82%	- 3%
Event materials	83%	93%	+ 10%
Group discussions	85%	88%	+ 3%
Presentations	91%	94%	+ 3%

Most liked – observations volunteered by 68 attendees

- 47: Presentations
"Only time we have received first hand knowledge of CLL, only other info has been via internet." "Nice clinical info for the lay person." "Access to reliable information." "It inspires confidence to know about current developments and the range of options available." "Explanation of the disease." "Very down to earth and approachable." "Graphics on the slides really help." "I have been to many conferences and felt this one was more relevant." "Presentations by experts in their field."
Piers Patten on latest treatments available on the NHS: 11 citations
Samir Agrawal and Pauline Stow on the Remote Care Programme: 8 citations
John Gribben on CAR-T cell therapy: 5 citations
- 32: Meeting others and sharing experiences
"Being in a supportive group." "Meeting others with CLL, talking about problems etc, talking to consultants and research specialists." "Interaction with patients, but not as CNS, so seemed more open conversation." "The enthusiasm and commitment of the CLL community." "Meeting people with similar condition, still getting my head round watch and wait." "Sitting at tables in the round, very friendly." "The camaraderie."
Discussion groups: 5 citations
- 3: Learning more about CLL.
- 2: Venue/Location.
- 2: Food.

Least liked – observations volunteered by 57 attendees

- 39: The cold hall
"The room though impressive was cold." "Far too cold." "Uncomfortably cold."
- 6: Nothing
"Nothing." "All very good."
- 5: Toilet facilities
"The journey to the toilets." "No comfort break in morning."
- 4: Group discussions
"Carers's needs – no carers in my group." "Not relevant to me." "Struggled with group discussion- facilitator spoke very quietly." "Group discussion too regimented."
- 3: The food
"Food poor." "Only two herbal tea bags, no labels on food."
- 2: Microphone use. Sound quality.
- 1: Made me more nervous about CLL, more to think about.
- 1: Slides on screen unreadable from back of room.
- 1: Repeat of previous CLL talk on Remote Care.

Coping with CLL: the role of the carer or supporter

This is an analysis and distillation of the notes submitted by nine discussion groups at the London 2017 conference. There were 72 participants, of whom 21 (29%) were carers or supporters. All groups were designed to include carers / supporters. Direct quotes are given in italics.

1. What do carers or supporters find difficult?

1.1. Getting to grips with CLL and what it means

- *Understanding CLL and accepting there is no cure*
- *Unknown, complicated jargon, lack of communication*
- *Understanding the difference between fatigue and tiredness*
- *Onset of infections*
- *Not told how to understand symptoms*
- *Being told "no treatment" i.e. watch and wait*
- *Trying to understand seriousness and treatment regime*
- *Delivery of diagnosis, communication*

1.2. Coping with change

- *Loss of previous life / change is difficult / unplanned lifestyle changes*
- *Sudden idea of being called a "carer"*
- *Uncertainty about the future*
- *Understanding what happens next*

1.3. Responding to the patient's mood

- *Coping with the patient's mood*
- *Different reaction to CLL (i.e. difference between patient and carer)*
- *Providing emotional support rather than physical support*
- *Patient reluctant to seek medical advice*

1.4. Practical aspects

- *How to tell people*
- *Travel insurance*
- *Getting advice*

1.5. Burden of being the carer

- *Caring is so difficult*
- *Daily grind of CLL*

2. What advice does the group have to cope with this?

2.1. Make the most of medical appointments

- *List together the questions to ask the consultant*
- *Partner to accompany patient to consultations and give feedback*
- *Take a dictaphone to the appointment, with GP / Consultant approval*
- *Track illness in order to report to the GP*
- *Consider changing the frequency of appointments*
- *Get good information*
- *Use CNS*

- 2.2. Allow the patient to rest and to take the lead
- *Allow the patient time to rest to cope with their mood / fatigue*
 - *Tolerance. Let the patient find their own route*
 - *Take lead from patient*

- 2.3. Remain positive
- *Be positive and enjoy life*
 - *Have a positive approach*

- 2.4. Let the carer seek support from others
- *Let them consult with others- family / doctors*
 - *The way you present your condition, e.g. describe as a blood problem rather than the "c" word*
 - *The disease magnifies the dynamics of existing relationships*

- 2.5. Ask the carer how they are
- *Ask the carer "how are you?"*

3. What do patients want from their carers or supporters?

- 3.1. Patience, understanding, empathy
- *Support when emotional or upset*
 - *Friends to just understand*
 - *No sympathy, knowing some one is there to support when needed*
 - *Acknowledgement of the issue*
 - *Balance your support: when well worry less. When we are ill, then we need your support*
- 3.2. Help to keep things in proportion
- *Stay as close to normality as possible; the carer can be a lifeline to reality and keep you sane.*
 - *Quietly cover the basics; keep the bigger picture*
- 3.3. Help with living sensibly
- *Partner to insist on taking time out when tired*
 - *Support for making the Healthy Life Plan work.*
 - *To be challenged when doing too much / not realizing when this occurs*
- 3.4. Help with making the most of life
- *A gin and tonic!*
 - *Keep the social / family calendar*
 - *Positivity / support to plan the future*
- 3.5. Be watchful; ask questions at appointments
- *Watch our condition: be observant*
 - *Attend appointments and ask questions*
- 3.6. Be honest about how you are feeling
- *Give an honest answer to the question: how are you?*

4. How can carers or supporters best meet these patient needs?

4.1 Seek external support and advice

- *Local support groups would be helpful*
- *Macmillan gives support to carers on this*
- *Need for a local group with advice, professional guidance*
- *Helpline with clear advice, for example shingles as a side effect*
- *Attend meetings*
- *Ensure close family are aware of processes*

4.2 Be a partner in care

- *Be equal experts with the patient*
- *Assist in maintaining appropriate diet /life style*
- *Help at home when fatigue sets in*
- *Speak up at the doctor's*
- *Meet the patient with a similar attitude, if it doesn't bother the patient, prefers not to have fuss*
- *Be there for appointments*
- *Listen, empathise*
- *Help with understanding*
- *Research*

4.3. Don't over-react and don't give up

- *Take the patient's lead*
- *Live with it, don't die of it*
- *Appreciate the good. Value the here and now*
- *Not "molly coddle" unnecessarily*
- *Don't give up easily*

Three Wishes

A group discussion exercise at the London Conference, 7 November 2017

This exercise was designed to help the CLL Support Association determine members' priorities for a good patient experience of care.

Participants were asked to assume that they had none of the 7 options listed below. As in fairy stories, they were allowed just three wishes. Their choice was limited to the list. A cure for CLL was not allowed. Their three chosen wishes are recorded in the A columns in the table below.

They then conferred in mixed groups, of 6-9 participants each, to determine their collective top three wishes. These are recorded in the C column in the table below.

The 7 options

1. Access to a consultant haematologist, with a special interest in and experience of CLL.
2. Advice on where to access reliable information to meet my needs.
3. An opportunity to meet locally with others affected by CLL, both patients and carers.
4. Access to a clinical nurse specialist for CLL.
5. Access to counseling for the psychological impact of a CLL diagnosis on me and my family.
6. Advice on diet, complementary therapies ("and exercise", added by some participants).
7. Other. Only one volunteered and chosen as a top wish: An informed and interested GP.

	-----A-----						C	
	w & w patients	patients under treatmnt	patients post treatmnt	all patients	carers	health care profs.	all indivdls.	all groups
1. Consultant	100%	100%	100%	100%	100%	100%	100%	100%
2. Information	58%	40%	40%	53%	51%	100%	55%	28%*
3. Meet others	36%	80%	40%	42%	30%	-	37%	61%
4. CNS	47%	20%	60%	45%	57%	100%	50%	44%
5. Counselling	29%	20%	40%	29%	37%	-	30%	28%
6. Diet, complmnt.	27%	40%	20%	28%	26%	-	26%	28%
7. Other: GP	3%	-	-	2%	-	-	2%	11%
Sample size	33	5	5	43	19	3	65	9 groups

*Note: Some argued that, with access to a consultant with a special interest in and experience of CLL, as well as a CNS, patients and carers would be able to get advice on reliable information to meet their needs.

This may explain why the score for information in column C is unexpectedly low.

Key Findings

1. Participants were unanimous that the top priority is access to a consultant haematologist with a special interest in and experience of CLL.
2. Patients and carers, as a whole, tended to agree with healthcare professionals that the top

three priorities are: access to a consultant haematologist with a special interest in and experience of CLL; access to a CNS for CLL; advice on reliable information.

3. The softer aspects of care – meeting others affected by CLL; access to counseling for the psychological impact of a CLL diagnosis; advice on diet, complementary therapies (and exercise) – are a significant priority for many participants.
4. Group priorities do not always mirror individual priorities. There is an unexpectedly high score for meeting locally with others affected by CLL in the group returns: 61%.
One watch and wait patient (column 1 in the A section of the table above) who had volunteered : “an informed and interested GP” as being one of his/her top three wishes successfully persuaded the whole group to adopt this as one of their three wishes (section C of the table).

Follow-up actions agreed by the Board of Trustees on 27 November 2017

1. CLLSA will consult the clinical community on how to advise members about accessing a consultant haematologist with a special interest and experience of CLL.
2. CLLSA will support Leukaemia CARE’s action to promote patient access to a CNS.
3. CLLSA will continue its priority of producing reliable patient information on CLL.
4. CLLSA will consider its policy and practice on the softer aspects of care: counseling; complementary therapies, diet, exercise.
5. CLLSA plans to list local support groups nationwide in 2018 and promote the launching of new ones in response to demand measured in its recent electronic survey.
6. The role of the GP is a possible topic for a CLLSA conference in 2018.
7. Interest in local support groups for CLL, expressed in the “three wishes’ exercise at Barts, is in line with the views of members in the recent CLLSA survey. A research project to map existing groups would be beneficial, prior to responding to the localities of interest revealed in our survey. CLLSA will explore the case for working in partnership with other charities in the Blood Cancer Alliance on such a project.
8. The Board recommends a further study of member perceptions at conferences in 2018. This will measure how important to members the seven aspects listed in the Three Wishes exercise at Barts are and patients’ experience of each. This may act as a pilot to a fuller electronic survey. It should yield a more informed picture of members’ priorities for CLLSA to action.

CLL SUPPORT ASSOCIATION**London Conference 7 November 2017**

Great Hall at St Bartholomew's Hospital (Barts), West Smithfield, London EC1A 7BE
between Farringdon, Barbican and St Paul's stations

Programme

- 10.00 **Arrival.** Refreshments
- 10.30 **Welcome** and introduction. Olga Janssen, CLLSA trustee
- 10.40 **Latest CLL treatments available on the NHS** Dr Piers Patten
To include current clinical studies and a question and answer session.
Piers Patten is a Consultant Haematologist at King's College Hospital, London. He has a particular interest in CLL both through his research in the lab and his involvement in an extensive clinical trials portfolio.
- 11.40 **Coping with CLL** small group discussions
An opportunity to share, with others who live near you, your experience and tips for coping with CLL, with a special focus on the role of carers / supporters.
- 12.20 **The Remote Care Programme** Dr Samir Agrawal, Pauline Stow
A recent survey of the patient experience of the Programme.
Samir Agrawal is a consultant haemato-oncologist at Barts, and senior lecturer in haematology at Queen Mary University of London. His research includes the design and implementation of studies on CLL, in which he has a specialist interest. He is an expert in the field of infection in immuno-compromised patients with cancer. His current activities include systems for "remote care" for patients and empowering patients by giving them their data through secure online databases. Samir Agrawal is a trustee of CLLSA.
- 1.00 **Lunch**
- 2.00 **CAR-T cell therapy** Professor John Gribben
A new cancer therapy, which has done well.
John Gribben is Centre Lead for Haemato-Oncology at Barts Cancer Institute and Professor of Medical Oncology at Barts Hospital. He is President Elect of the European Haematology Association. Prof Gribben has published over 400 papers and is a founding member of the CLL Research Consortium. He is a recipient of the Rai-Binet Medal in recognition of his lifetime achievement in CLL Research.
- 2.20 **CLLSA goes local** Olga Janssen, CLLSA trustee
Exploring options for local support groups
- 2.30 **Three wishes**
Small group discussions to help CLLSA determine members' priorities for a good patient experience of care.
- 3.10 **Tea**
- 3.25 **Patient/Carer CLL stories** Surjeet Soin, Gail Wiegman
- 3.55 **Closing comments and next steps.** Olga Janssen
- 4.00 **Departure**

CLL Support Association
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