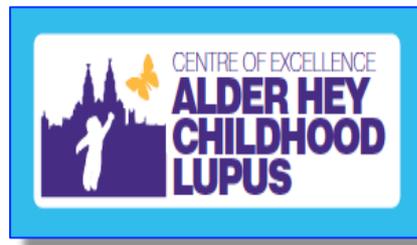




Alder Hey Children's **NHS**
NHS Foundation Trust



UNIVERSITY OF
LIVERPOOL

Lupus and You

Workshop for young people with Lupus and their families

Report



Alder Hey Children's NHS Foundation Trust
19th March 2016

**Report by The Lupus Team,
Centre of Excellence for Childhood Lupus at
Alder Hey Children's Hospital**

Background

Why a workshop?

The development of a workshop for young people with Lupus and their families attending the UK's only paediatric Lupus Centre of Excellence at Alder Hey Children's Hospital was indicated for a number of reasons:

- Lupus is an autoimmune disease that can affect any organ in the body. It is rare in children and young people under the age of 18. Discussions within clinical practice revealed that most patients within our service had never met another young person with the condition and how isolating this could feel. Similarly parents and siblings wondered whether the concerns they felt for their children's health and future were unique or indeed might be shared amongst other families.
- The mental health needs of young people with chronic health conditions are well known and as a service we wanted to both support those needs as they arise whilst also looking to intervene proactively to give the young people the skills, networks and resources to develop resilience and coping strategies to minimise the impact of their condition and support them to live life fully.
- As a regional service and the UK's only paediatric Lupus centre of excellence, our patients are spread out across a large geographical area. Travelling to additional appointments is therefore challenging both in terms of time taken away from education, work and social commitments but also due to the physical exertion required in the context of symptoms that often include fatigue and pain.

As a result, a day-long workshop was developed to be attended by the young people with Lupus and their families located within the Institute in the Park on the familiar Alder Hey Children's Hospital site. The event was developed and run by representatives from the Lupus multidisciplinary team as well as colleagues from the hospital research facility involved in studying Lupus.

Focus on Fatigue

As part of routine clinical practice, all Lupus patients and their accompanying parent or guardian are asked to complete a clinic screening tool to help them to provide a snapshot of their Lupus related concerns in the weeks leading up to that clinic appointment. It is also designed to help patients to prioritise issues for discussion within that consultation. It was from this data that the topic of Fatigue was identified as a focus for the workshop as this was one of, if not, the most commonly reported symptom of concern reported by both young people with Lupus and their parents.

Focus on Research

We recently held an away day for the UK JSLE Cohort Study Group (more detail below) which was attended by some patients and parent representatives. These representatives were really interested to hear about all the research being carried out and suggested that other families may also be interested to find out more. Additionally a recent survey of some young lupus patients found that

very few were aware of the UK JSLE Cohort Study. We therefore felt it would be helpful to dedicate some of the day to discussing research.

Attendees

The workshop was attended by:

- 9 staff members representing both the multidisciplinary team and research facility
- 7 families including
 - 6 young people with Lupus
 - 2 siblings and
 - 10 parents
- Mr Kevin Weston, Chair of Lupus UK, also attended in order to represent the charity. As a parent of someone with Lupus himself he also actively participated with the parents' activities.

Introductions and Icebreaker

After making the long journey on a chilly March morning, the young people and families arrived to a hot drink and biscuits. After making some informal introductions, staff and attendees were all encouraged to take part in an ice-breaker exercise involving sharing information about ourselves –the number of details shared corresponded to the number of toilet paper squares torn from the roll-needless to say this prompted some smiles and did a great job of relaxing the group and setting up the tone of conversation and collaboration for the rest of the day.



Fatigue Workshop

Attendees were split into two groups; young people in one and parents/family members in the other.

A number of discussions were facilitated to consider the following:

- **What is fatigue?**

Young People	Parents
Exhaustion	Fatigue! Mental or Physical
Overwhelming tiredness	Annoyance / Stress
Emotional	Tiredness
Irritable	Tiredness / Weak feelings / feeling overwhelmed by a lot going on
Argumentative	Tiredness/ Weakness

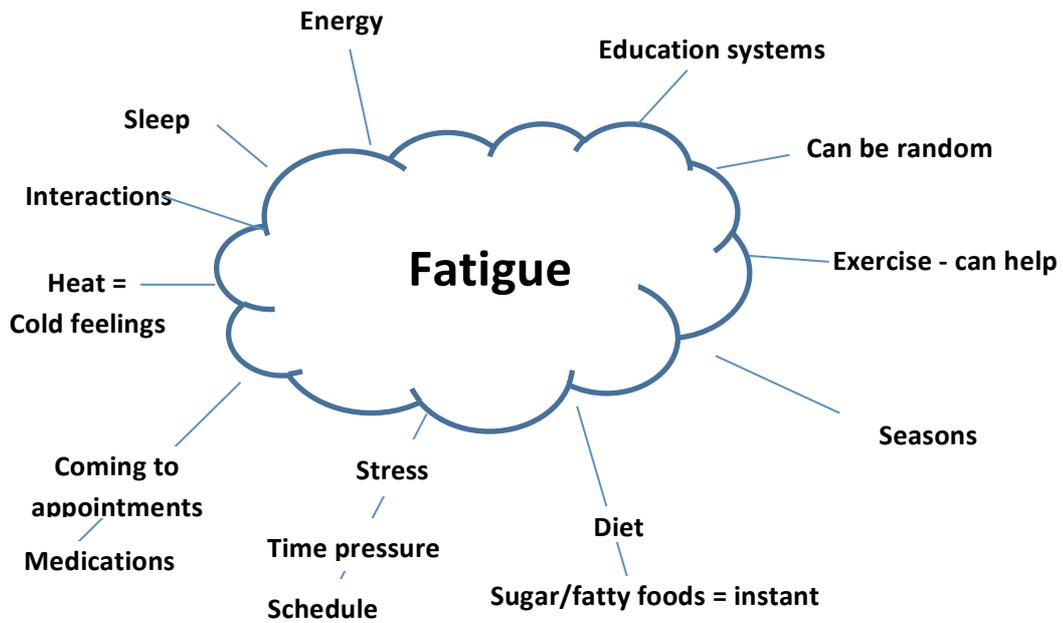
Difficulty distinguishing normal teenage behaviour and lupus fatigue	Build-up of emotions that make you feel distracted, worn out, drained
Mental more than physical	Lupus Rash
Exercise doesn't help	Body feels drained and heavy
Difficulty concentrating	Different to not having enough sleep
Pressure to be normal	Tired / grogginess/ lethargic / heavy
Anxiety	Body shut down
Tearful	Drained / hard to describe
Stigma -Don't want people to know I have disease	Too warm / unhealthy eating
Waking up tired	Annoyed and frustrated with everyone when fatigue increases
Not being able to sleep due to worrying	Motivation
	When I feel tired

- **What impact does it have on your life?**

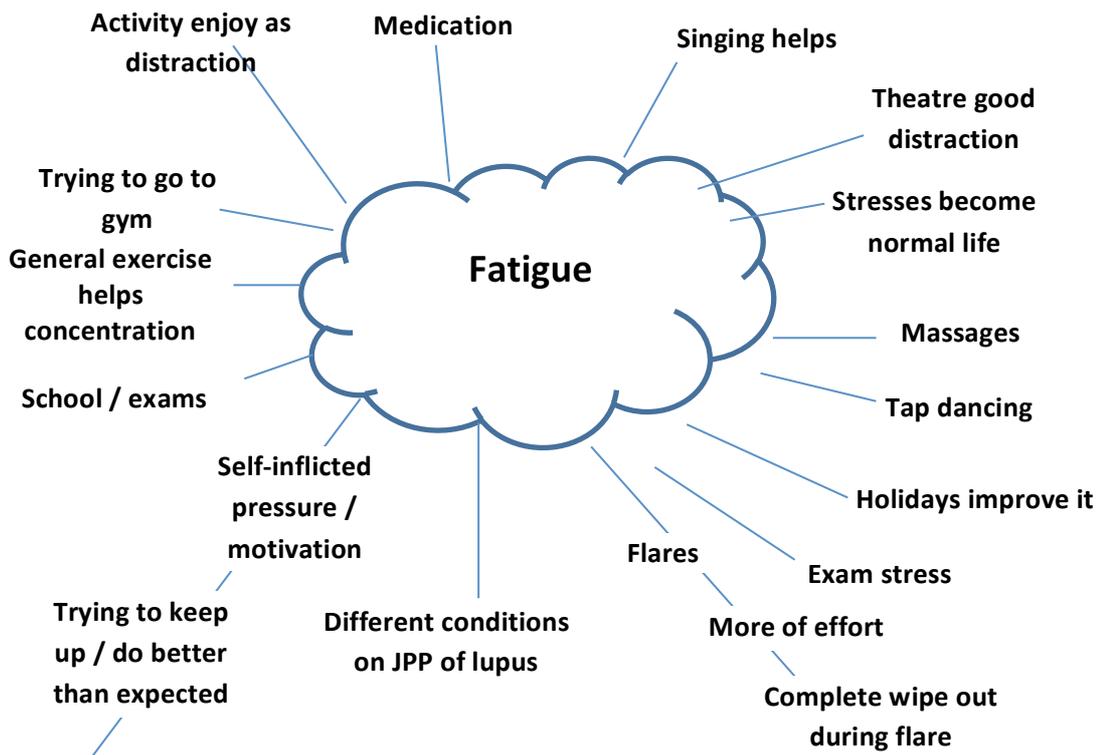
Young People	Parents
Revision / Gym	Stigma
Horse Riding	Fear → trying to keep up
Future	Restriction → Plan day / less spontaneous
Can't keep up	Help and understanding from teachers
School / Mood / physical activity	Mentally a bit slow
Can't work in fashion / medicine / accountancy / investments	React less
↓ Motivation – falls behind in school then trying to catch up ↑ fatigue	Brain Fog
9-5 jobs – consideration of fatigue	Avoid trying to think
Relationships	Clash with siblings → laziness
Frustrated	Extra time / breaks in exams
No motivation – can fall behind on work at school / college etc.	Lack of confidence
Feel like I'm on my own	Try plan for a week
Do first & think later	Unexpected plans throw off plans
Jobs, what can you do, college, GCSE revision?	Work / life balance
Stop enjoying everyday life	Coping mechanism
Tired after school / college so don't go out with friends – lack of a social life compared to friends	Rest, breaks in day
Stops me playing football and other sports	

- What influences how fatigued you feel?

Young People said: "Its like a shadow..."



Parents said:



**Not wanting lupus
to beat them**

- **What have the families and young people already done to try to manage fatigue?**

Young People	Parents
Going for a coffee etc. when on a day out	Massages
Elevate legs	Limiting chores at home
Re-assurance	Prioritising things (there may be differences of opinion – parent/child/yp)
Routine – boring but necessary	Outside interests aid work/life balance
Exercise	Having friends with a similar outlook (like staying in for example)
Resting	Sharing info with others on lupus
Pre-planning	Having options / provide options / solutions – different perspectives
Relaxation	Dealing with stressful circumstances
Time and space alone	Support their decisions / plans
Rest / break	Plans with pre-planned flexibility
Sleeping	Breaking down tasks into steps
Mentor/ friendly teacher to go to school	
Using lifts	
Pamper day e.g. bath	
Swimming	

These issues were considered in the context of a case discussion of a young person juggling the challenges of Lupus in the context of everyday life

Emily Wilson (Clinical psychologist) shared information regarding the role of psychology in supporting a young person with fatigue, focussing on the relationships between thoughts, feelings and behaviours.

Katie Dobson (Occupational Therapist) and Sue Kemp (Physiotherapist) discussed the importance of setting goals, managing activities, pacing and taking regular exercise.

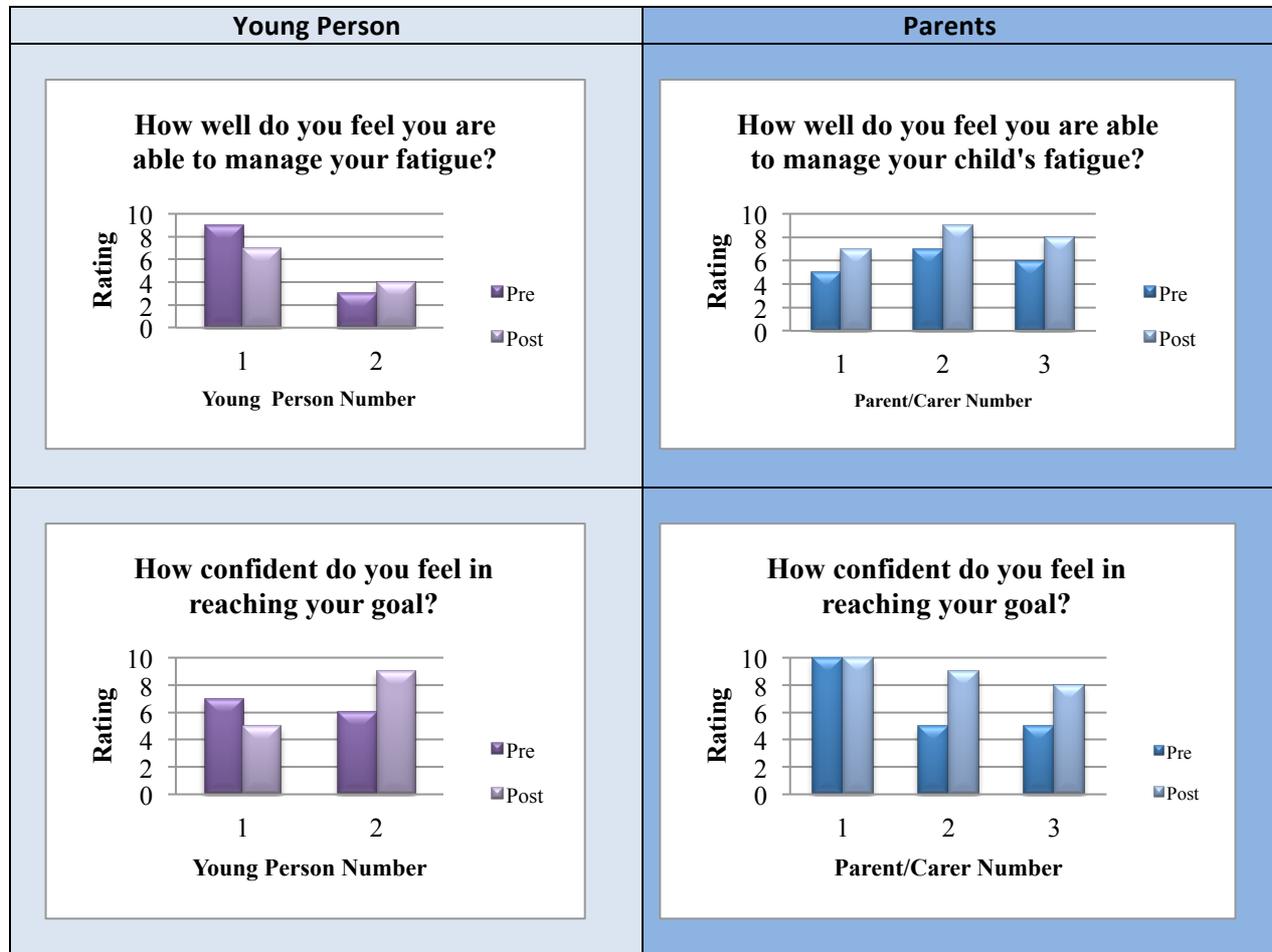
All activities and discussion points were included within a workshop booklet given to all attendees. Information was also included regarding sleep hygiene, relaxation strategies, health eating and healthy lifestyles.

Fatigue Data

In order to consider level of fatigue amongst the group, the young people were asked to complete the Chalder Fatigue Scale and the Fatigue Severity Scale. The mean (average) score on the fatigue severity scale of patients attending the day was 5.1 (range 4 – 5.8) where people scoring above 3 points are considered to suffer with fatigue. This data therefore suggests that lupus patients do suffer with fatigue.

Young people and their families were asked to rate their perceived ability to manage fatigue and their confidence in being able to manage things better. The results compared their views before the fatigue workshop and again after. The results are below:

In all bar one case, participants indicated that they felt more able to manage fatigue and more confident in reaching their fatigue related goals following the workshop.



Measures of Emotional Well-being and Quality of Life

Over the course of the day the young people and their parents were asked to complete some standardised questionnaire measures capturing data on emotional well-being (Paediatric Inventory of Emotional Distress), Resilience (Resiliency Scale) and Quality of life (PedsQL Core Module).

These scores suggested there was considerable variation in the extent to which young people were affected by and were coping with having lupus. The results will be reviewed with the individuals and their parents in order to inform ongoing intervention and support.

Research Workshop

We started off this session by giving an overview of what research is and then specifically moved on to describe the research that is going on in Liverpool and the rest of the UK, as part of the UK JSLE Cohort Study (see below for full description of the Cohort Study). Patients and families were then

invited on a tour of the lab at the Institute of Child Health, University of Liverpool, Alder Hey Children's hospital, where much of our laboratory research into lupus takes place.

Explaining the UK JSLE Cohort Study



In 2006 a group of leading UK Rheumatologists formed The JSLE Study Group. The UK JSLE Study Group is a multi-disciplinary group of paediatric rheumatologists, nephrologists and dermatologists, adult rheumatologists, nurse specialists, lay representatives and basic scientists from all over the UK. Its members represent almost all of the major paediatric centres in the UK. The UK JSLE Cohort study is the study run by this group. It aims to find out more about what causes lupus and how it affects children and young people, in order to try and develop better treatments.

The Cohort study recruits patients aged up to and including 16 years of age from more than 20 hospitals all over the UK. It started recruiting patients in 2006 and over 550 young people with lupus from across the UK have taken part so far. We have undertaken a wide range of research looking at the immune system, genetics and treatments in lupus. We publish our research in various medical journals and discuss our results with other researchers around the world to help generate new ideas on how to help look after patients with lupus.

Laboratory Tour

Researchers in the lab are looking at different parts of the immune system to help find specific targets for treatment. Patients with lupus support this directly by donating extra blood for research purposes. During the meeting we showed the group what happens to their blood in a video that the team have developed. We pointed out the machines used for different types of experiments. In the next part of the lab tour the patients and their families got the chance to look at some immune cells under the microscope. The first demonstration included cells that had been exposed to bacteria and were then 'eating it'. This process was demonstrated under a confocal microscope, which can show different fluorescent colours. The DNA of the cells was stained blue and the bacteria became red only once eaten.



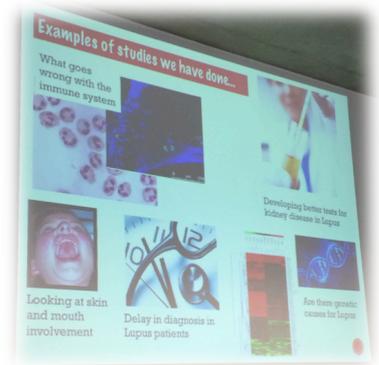
The group were then shown a slide of stained neutrophils (another type of immune cell) under a light microscope. We explained what we look for to know that a cell is a neutrophil. It is very important that only neutrophils are isolated for our experiments, we don't want our experiments being affected by other cell types! We then got them to 'spot the PBMC' as this is a type of cell we want to exclude, and described the differences between the cells. Parents and young people asked questions about the problems the immune system has in lupus and wanted to know more about how experiments are

prepared. Everyone seemed very interested in what we do and what we hope to achieve with the research.

A short video demonstrating how we isolate the different types of white blood cells for research is found at this link: www.youtube.com/watch?v=EHbkvGNDg-A

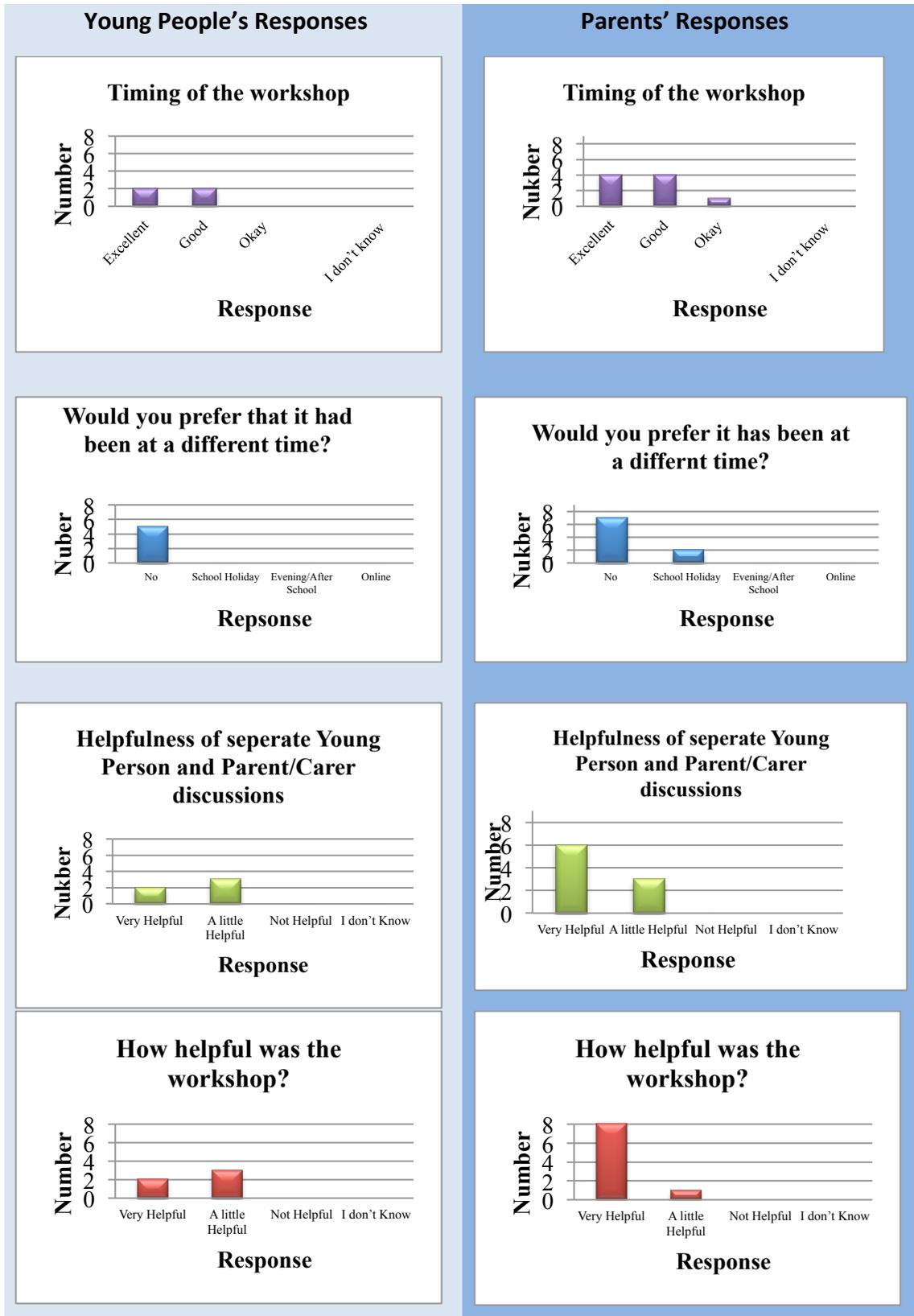
Updating families about research

We asked patients and families if they wanted to know about research and if so, how they would like to find out about it. All the patients and families attending the day said they were interested in and keen to find out more about research. Most families already follow LUPUS UK on Facebook and felt this was a useful forum through which we could share new information. Families were happy to receive emails and felt they would read information that was sent to them this way. Some patients and families used Twitter but many said they didn't. Other suggestions included a UK JSLE Cohort Study Facebook page and I-tunes podcasts. This session highlighted that different communication methods suit different families and moving forward we hope to improve how we communicate our work in different ways.



Evaluation

All young people and their family members were asked to complete an evaluation form prior to leaving. As can be seen from the following data, attendees found the workshop to be helpful and convenient to attend.



Further information provided by the young people and parents is detailed below.
Young people

1) What did you find most helpful?

Young People	Parents
<i>Meeting others with Lupus</i>	<i>Talking to/meeting other parents/carers of children with Lupus</i>
<i>Tour of the Lab</i>	<i>Discussions/exchanging experience with other parents</i>
<i>The workshop</i>	<i>Tour of Lab</i>
<i>Fatigue workshop</i>	<i>Fatigue workshop</i>
<i>Seeing how others manage their fatigue</i>	<i>Whole event was excellent</i>

2) Is there anything you found unhelpful or you have not enjoyed?

Young People	Parents
<i>No</i>	<i>No</i>
<i>The party bit [a case scenario about attending a party]</i>	<i>Wondering if this is relevant due to individual nature of my child's illness?</i>

3) Would you be interested in attending future workshops?

Young People	Parents
<i>4 maybe</i>	<i>4 Yes</i>
<i>1 Yes</i>	<i>4 Maybe</i>

4) What topics would you like to cover in future workshops?

Young People	Parents
<i>Support for siblings</i>	<i>Medication- how it works and its side effects</i>
<i>How you treat lupus</i>	<i>Common symptoms</i>
	<i>Research and Communications progress</i>

5) Are you interested in being involved in a Northwest Lupus support group for Young people with Lupus?

Young People	Parents
<i>2 Yes</i>	<i>5 yes</i>
<i>3 Maybe</i>	<i>3 Maybe</i>
	<i>1 No</i>

- 6) Would you be interested in helping promote the work of UK JSLE Cohort Study to help other Young people with Lupus understand what the study is about?

Young People	Parents
3 <i>Yes</i>	5 <i>Yes</i>
2 <i>Maybe</i>	3 <i>Maybe</i>
	1 <i>No</i>

Next Steps

The day concluded with a summary of the day's discussions and consideration of next steps. Attendees commented on having had an enjoyable day.

All attendees will be contacted by letter to thank them for attending and to encourage them to be in contact should they have any questions or queries from the day that they might like to follow up on with a member of the team.

Discussions are now being held within the lupus multidisciplinary team to consider possible topics and dates for a future workshop.

A short summary of the day will also be shared with Lupus UK and a blog will be posted on the GenerationR website: www.generationr.org.uk