

Newsletter



Introduction to Patient | Carer Community

Welcome to the first issue of the Patient | Carer Community (PCC) newsletter. The purpose of the newsletter is to provide members with a regular update on news and teaching activities and is written by members of the PCC like you!

The PCC is a community of patients and carers working in partnership with students, educators and clinicians, leading the way locally and nationally in educating the medical profession. We are making a difference by putting real stories at the heart of the curriculum so that patients, carers and family members everywhere will experience the best possible health care.

We welcome contributions from all members of the PCC in reports on activities you've been involved in, good news you'd like to share. I hope you enjoy reading this; please contact me if you have any comments, or suggestions for future editions.

Brian Clark & Shelley Fielden, PCC Members pcc@leeds.ac.uk

New Arrivals

I would like to take this opportunity to introduce myself to you as I will be covering Karen's role as Patient | Carer Community Coordinator, while she's on maternity leave. I may have already been in contact with many of you through my role as Communication Skills Coordinator; organising events such as the Home and Classroom visits. Karen has done some great work getting the PCC established and I'm very excited to be a part of the team; I'm really looking forward to working with you over the coming months. I'll be working two and a half days per week for the Patient | Carer Community; my contact details are below.

Nicola Lawlor

Patient | Carer Community Coordinator
Office phone: 0113 343 1656
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Congratulations to Karen Ayres, PCC Coordinator who gave birth to a baby girl weighing 6lb 13oz on Wednesday 24th October 2012. Karen and her partner Andy have called the baby Milla Ayres-Prestwich and all are doing well.

Health Foundation

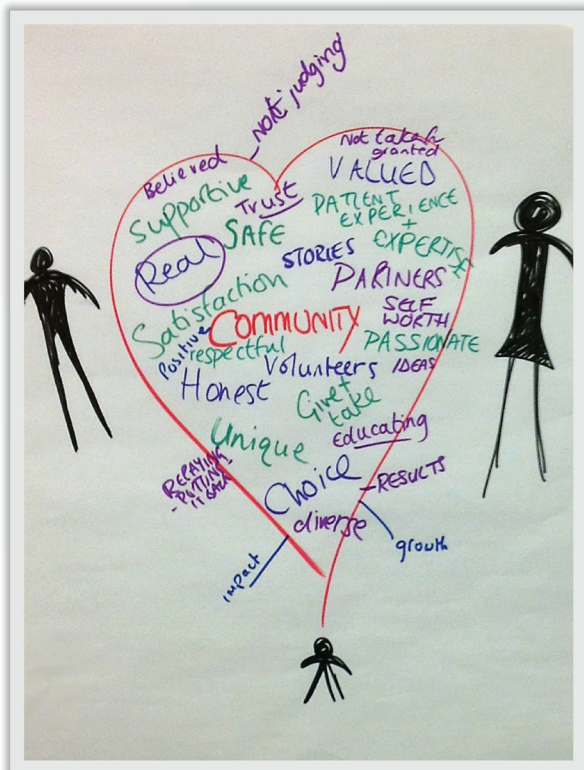
I'm lucky enough to work with lots of different people and organisations, but every so often I come across a group that really inspires me. PCC is one of those groups.

Over the last few months, Ben and Jonathan (my fellow consultants) and I have held four workshops with Jools, Karen, Nicola and a number of PCC members and

LIME staff to look at how to grow and strengthen the Community, as part of the Health Foundations Network Support Programme. Two things have really stood out for me:

Firstly, the dedication and passion of everyone involved in the PCC. We worked people very hard but their commitment never flagged.

Secondly, how easily everyone got to grips with the complex tasks we gave them. PCC members already had many talents to draw on, but some discovered new talents in the process. For example, Brian Clark, who worked with us on making the business case to possible funders about the great job the PCC is doing, said afterwards, before this workshop, I would never have thought I could do something like this. But I found I had skills I didn't know about!



Perhaps that's why the PCC is so inspiring - it's putting patients and carers remarkable stories, skills and talents right at the heart of training the next generation of doctors. We will all benefit from that.

So, a heartfelt thank you from all of us for the opportunity to work with the PCC this year. Keep up your great work!

Sophie Edwards

Member of the Health Foundation Networks Support Programme Faculty

Stop Talking, Start Doing.

On the 14th March 2012, The Strategic Clinical Skills Advisors for NHS Yorkshire and the Humber and Leeds Metropolitan University, hosted a national 'Stop Talking and Start Doing Conference. The 2nd annual conference addressed the Physical Health Agenda for Mental Health and Learning Disabilities through: Clinical Skills and Simulation, Education and Training.

The conference focused on four key areas:

- 1) Insight into the physical health needs within mental health and learning difficulties;
- 2) How to improve clinical skills and knowledge base;
- 3) The need for a better understanding and awareness of mental health and learning disabilities issues in Primary Care; and
- 4) Promoting interprofessional clinical skills training.

Susan Thornton, a member of the Patient | Carer Community, spoke at the conference about her personal experience of A&E: We only deal with Physical Health or Mental Health; its one or the other! Karen Ayres, Patient | Carer Community Coordinator caught up with Susan after the conference:

What did you enjoy the most about the Stop Talking, Start Doing conference?

It made me feel as though we're finally making progress, as slow as it may seem, in having clinicians start to treat physical and mental health problems holistically. They seem to have a greater understanding of the impact of mental health on physical health, and vice versa, and this makes me feel very positive about the future. It's also good that clinicians are coming together to share best practice and avoid unnecessary duplication of work.

If someone wasn't able to go to your session, what would your take home message be for them?

I think it would be to get them to start investigating whether or not there is a mental health condition when someone presents with a physical health condition rather than just treating the physical health condition and dismissing the mental health condition. I also want to get across the idea of when does the clinicians role stop? In other words, don't just treat the one bit you're responsible for (e.g., Broken arm) but check to see if there are any mental health issues as well that should be considered (for example, my mental health problems led to me breaking my arm in the first place). Investing in early intervention is much more cost-effective than dealing with the aftermath

For more information about the 'Stop Talking and Start Doing Conference, please visit - <http://goo.gl/DwPTo>

Community News!

Congratulations to PCC member Susan Thornton who was awarded a bronze medal in the Leeds in Bloom 2012 Private Gardens awards at Leeds Town Hall in July. As you can see from the photograph Susan is a keen gardener and the award is thoroughly deserved!



UpBete Award Win

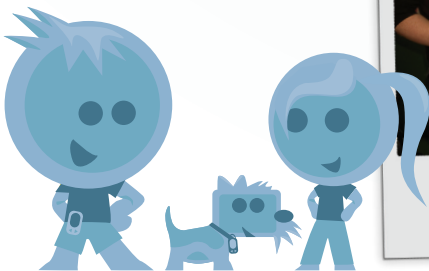
Congratulations also to PCC member Naseem Akram who has successfully completed her Preparation for Higher Education access course at the University of Leeds. Naseem has been offered a place on the Health and Social Care degree course at the University of Bradford but plans to defer further study until 2013 as she is exploring degree courses at the University of Leeds which is her preferred university.

We are very pleased to announce that UpBete has recently won no less than two separate awards. Our first award win came from the Bupa Foundation in their Patients as Partners category our second award came from Medipex in their Software and Telehealth category.

For those not in the know, UpBete is an online support service for children and young people with Type 1 Diabetes. UpBete has contributed to a significant rise in the number of children in Leeds with good diabetes control. The UpBete website design was developed in collaboration with patients and their families and PCC members are still very much active in the services continued development.

From left to right: Scott Hennessy, Lee Gill, Jools Symons, Gareth Frith

Upbete



Teacher as Patient becomes Patient as Teacher

Kay Henderson reflects on being part of the Patient | Care Community having first got involved in activities at the School of Medicine in 2003. In addition to home and classroom visits Kay was involved in the development of the Patient Learning Journey programme, has worked as both a simulated patient and facilitator on communication and interprofessional education courses, presented at national and international conferences, run workshops and has been involved in developing case scenarios for use in teaching.

I feel proud to be a member of this team for several reasons, one of which is that we are recognised by the University as having a vital and valid place in several areas of medical education. Another is the personal value I feel from being part of a team, with all the support and friendship that goes with it. We are aiming for the same goal - preparing students to be the kind of doctors we need and want and we help each other towards achieving it.

Working with medical students has had major impacts on my life. I shifted from feeling I had nothing much to offer when my career as a teacher ended because of ill health, to feeling I had a purpose again. As a result I felt more positive and confident. My self-esteem increased and I had things to look forward to. I managed my illness better because I wanted to continue being a part of the whole wonderful experience of working at the medical school. I was and am still determined to do it and the pleasure and satisfaction it still gives me has made painful joints much more bearable. I actually think my health has improved because of it. It has also made a difference to family and friends who can hardly believe the change in me.

Depression is a thing of the past and those around me reap the benefits of seeing me so very happy and involved. I am much less dependent as I have so many other things to focus on.

The other major impact of being involved with medical education is in me as a patient and the way I feel towards doctors. In the past I was much more passive, believing it was



From right to left...
Kay Henderson, Joan Hardy
and Joannie Tate

a doctors job to treat me. I now realise what I need to do in order that a doctor may do his job well. Learning what is required of students and helping them achieve it has shown me the difficulties they can experience. I feel sure I am now a much better patient when I see my own doctors and consultants. I think in terms of it being a partnership. I am confident to share my expertise with doctors, challenge their opinions if need be and be involved in any decision making. I come away from consultations feeling much more satisfied.

I hope to be involved in medical education for some time to come. Over the long summers I miss both the work and the contact with others in the team. We have become like a large family and genuinely support and care for each other. I think about my old life less and less. Whilst ever I am needed and can drag my bones to the Medical School, I'll be there!

Kay Henderson, PCC Member

Higher Education Academy

In December 2012 the Patient | Carer Community hosted the first Higher Education Academy Lived Experiences Network (LEN) meeting. The national Network is led by Jools Symons – Patient and Public Involvement Manager at Leeds Institute for Medical Education. The Network purpose is to be a forum for people's lived experience of health and social care; a critical alliance of people with real experiences, students and academics for the purpose of improving practitioner education and associated research in health and social care. The group identified a number of strategic directions to support its purpose:

- To gain local, regional and national influence
- People who use services informing people who work within the service
- To provide education which is aspired to by others
- To create opportunities to meet people we may not normally meet
- To create sustainability; identify funding for this network and for involvement
- To politicise and to support patient and carers involvement in Higher Education
- To develop an alliance between practitioners, patients & carers and students
- To maintain democratic communication amongst teams
- To ensure co-operation by all members –a focus on value not competition

In the mornings showcase; Jools Symons, David Blythe, Kay Henderson and Joannie Tate (PCC Members) shared their personal stories of supporting medical students at the University of Leeds. This included how and why they became involved, and how the students, staff and themselves benefit. The presentations were a clear demonstrations of the passion they feel about being able to help educate the Doctors of tomorrow. The meeting was well attended and received great feedback:

“Can I also add how inspirational it was to hear...how much you can achieve if you keep on keeping on”



“Many thanks for yesterday’s get together, it was a really good day where lots of things got done. I found it really useful to chat to people about what they are doing, and I really enjoyed the presentations, which were all very helpful and interesting.”

“Congratulations on a powerful morning of storytelling and illustrating what is possible, I think it made a strong impact.”

“Thank you also for the wonderful warm welcome and fabulous hospitality.”

“It was educational and most of all inspirational...”

The next LEN meeting will take place 7th May and will be hosted by the Faculty of Health Sciences at the University of Southampton with a smaller working group action-meeting taking place in March at the University of Central Lancashire.

Jools Symons, Patient and Public Involvement Manager
Nicola Lawlor, Patient | Carer Community Coordinator

Calling all Patient Carer Involvement Volunteers

A DATE FOR YOUR DIARY

Opportunities to Learn



14 May 2013, 12 – 2pm at the University of Leeds

- Do you know that there are lots of opportunities for adults to study part-time at University?
- Have you heard about the Lifelong Learning Centre at the University of Leeds?
- Do you know that you can access FREE and impartial advice and guidance to understand the courses on offer and the financial support available?

This informal daytime event includes a FREE lunch and will give you an opportunity to find out more about the different types of courses for adults at the Lifelong Learning Centre. You will be able to meet staff and mature students who can give you information and advice and share personal experiences of studying at the University of Leeds. For more information please contact Greg Elliott, g.l.elliott@leeds.ac.uk, 0113 3431770

To register your attendance contact: Jools E Symons, j.e.symons@leeds.ac.uk
0113 3438833

This event is being jointly organised by the Leeds Institute of Medical Education and the Lifelong Learning Centre at the University of Leeds.

All Welcome!

Naseem Akram - Life Long Learning Champion (page 4) will be at the event to answer questions about being on the course

Autumn Term Review

Many thanks to everyone in the PCC for taking part in teaching activities this term. PCC members have been involved in a huge amount of teaching meeting students from across all 5 years of the undergraduate medical degree. Activities have included chats with students at home and in the classroom about life as a patient or carer, facilitation and simulated patient work on the communication skills and multidisciplinary team work courses, and new this year, involvement on the chronic disease management course with colleagues in Primary Care.

In addition to teaching, members of the PCC have also been involved in presentations at a number of national conferences, development workshops with the Health Foundation, the Higher Education Academy and in delivering the Patient Learning Journey programme for new members. Thank you for taking part and your continued enthusiasm for being involved and we look forward to working with you again next term.

Meet the team



In other news...

For the first time this year, the LIME Office held an 'Office Bake Off' in aid of Children in Need. The event raised a fantastic £76.50 which will help fund projects to help disadvantaged children across the UK. A big thank you was sent to everyone who contributed and in particular to all the bakers for getting into the spirit and providing such a wonderful spread.

The overall winner of the bake-off was our very own Nicola Lawlor, PCC Coordinator, for her Pudsey Bear creation. Congratulations Nicola!

