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Charities and NHS collaborate to support self-help groups and volunteers

Four national charities have joined forces with patients and the NHS in the East of England to model a new way of working in support of people with long-term health conditions.

The British Heart Foundation, Diabetes UK, Macmillan Cancer Support and the Stroke Association formed a partnership with the Strategic Clinical Networks (East of England) and some dedicated patient volunteers to launch a major event for the region.

Nearly a year's worth of planning and collaboration went into development of the first **Learn & Share Event for Support Groups and Volunteers**, which took place in Newmarket on June 11 with 180 delegates.

Individual charities and the SCNs came together in response to increasing evidence that people with long-term conditions in many cases have co-morbidities. There is also unilateral agreement on the need for supported self-management within a community setting.

Having healthy communities of volunteer-led support groups and assistance schemes is key to supporting individuals with long-term conditions, as a means of promoting education and the positive benefits of friendship and shared experiences.

Third sector organisations are best-placed to connect and develop these groups in conjunction with their regional NHS colleagues, as was proved at this highly successful event.

Keynote speakers from The British Heart Foundation and Macmillan Cancer Support helped set the friendly, informal but informative tone for the conference, ably chaired by patient representative Alan Bateman.

There were seven workshops on a range of themes:

- * **DIY websites for Support Groups**
- * **Healthy lifestyles**
- * **Good practice in starting and maintaining a support group**
- * **Tips and hints for fundraising**
- * **Improving local services**
- * **Imaginative self-help and support activity**
- * **An insight into Care.Data – how the NHS handles confidential health information**

Evaluation for the event as a whole, and for each of the individual workshops, was extremely positive. Comments included: 'Very worthwhile and beneficial day', 'Feel more confident and inspired about running a support group', 'Thank you for putting on this useful event. It was great to share with other groups', 'Networking with other groups was really helpful – think I will even set up a website!'

Particularly striking was the number of action-oriented comments coming through from the evaluation. These will be followed up in the next few weeks with a questionnaire to find out



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whether people have changed behaviour and/or made new networks and positive changes as a result of the day.

An often overlooked but equally vital aspect was the enthusiasm and excitement evident throughout the discussions and workshops, giving volunteers a much needed boost and renewed enthusiasm for their work.

Alan Bateman, one of the founder members of the Ipswich Head & Neck Cancer Support Group and chair of the event, said: "All of us running support groups go through peaks and troughs where we may find it difficult to recruit and carry on. That's when there's a danger that people could lose enthusiasm and quit, even though they may be providing a much-needed service for patients and their families.

"An event like this gives everyone a real boost. They can share ideas and feel that they are not alone. They also leave better informed and with a new set of 'tools' to help them continue. It is our way of saying 'Thank You' for all their hard work."

Justine Thompson, Patient & Public Participation for the SCNs, said: "This is the first time we have come together with individual charities in the East of England on a joint project. It was a great success and proves that we can work in an integrated, collaborative way for the benefit of people with long-term conditions."

Diane Card, East Region Development Manager for the British Heart Foundation, said: "Even when the nature of the illness is completely different, the emotions people experience are the same: fear, anger, grief and disempowerment. Condition-specific support groups are major providers of emotional support.

"This event was a great opportunity to connect up often isolated groups into a group-to-group support network based on the commonality of lived experience, rather than the difference in clinical condition. It was also a great networking opportunity for the national charities, so that we are all now more engaged with support groups and with each other."

Louise McAvoy, regional Macmillan Involvement Co-ordinator, said: "Collaborating with other third-sector organisations in the region made this event truly innovative and beneficial to attendees. All partners in the project have a shared goal of supporting people with long-term health conditions in the East of England. By combining our knowledge and experience we were able to deliver an event that reached more people and had more impact than any of us could have achieved alone."

Joanne Cloughton, Regional Support Officer for Diabetes UK, said: "Many people with diabetes also have an additional long-term condition. The event enabled those who attended to network with the various charities and learn from their chosen workshops."

Sara Betsworth, Regional Head of Operations for the Stroke Association, said "Meeting the health and social care needs of our growing and ageing population is becoming increasingly challenging. Opportunities like the Learn and Share Conference and working with like-minded charities helps us to ensure that our volunteers are equipped with the knowledge



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they need to do their valuable work, supporting stroke survivors in the community who are often living with more than one long-term condition.”

The Learn & Share committee has already agreed to hold another event in 2015. If you are interested in joining in or taking part, please contact justinethompson@nhs.net.