



Patient Information Forum

For everyone involved in health information and support

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Involving Users in Developing Health Information

AGENDA

Wednesday 17 May 2017

Resource for London, Holloway Road, London

Twitter: @PiFonline #PIFinvolving

9.30 – 10.00 **Registration and networking**

10.00 – 11.00 **Session 1: Setting the context**

Welcome from Chair - Professor Theo Raynor - Professor of Pharmacy Practice, Leeds University; Co-Founder and Academic Advisor, Luto Research

**A taxi from Bridlington - Lessons from people with heart failure
Professor Theo Raynor - Professor of Pharmacy Practice, Leeds University; Co-Founder and Academic Advisor, Luto Research**

Theo will set the context for the event, sharing recent work using Experience Based Co-Design (EBCD) in the development of information for people with heart failure. His presentation will address how involving users is not just the right thing to do – it makes a real difference; and how 'expert' patients and 'real' patients both have a role to play in developing good information.

Twitter: @LeedsHealthcare @lutoresearch @theoraynor

**From a patient's perspective
Trishna Bharadia - Patient Advocate**

Trishna will share her experiences of accessing health information and being involved in the development of patient related services.

Twitter: @TrishnaBharadia

11.00 – 11.25 **How do you involve users and what challenges do you face?**

Speed networking (including refreshment break)

This is your opportunity to engage with other event attendees, and make useful connections that will help drive your activities and projects forwards.

11.25 – 12.55 **Session 2: Involving users and understanding needs**

Listening to young women's voices

Kate Bria - Women's Voices Lead, Royal College of Obstetricians and Gynaecologists

Kate shares the RCOG's experiences of engaging young women in their work, to find out what they need to know and how to best get that information to them.

Twitter: @RCObsGyn @katebrian

Consulting black, Asian and minority ethnic (BAME) communities about their information needs

Claire Lucas - Information Services Manager, Alzheimer's Research UK

Claire will share an Alzheimer's Research UK project that is seeking to understand what health information will be useful and relevant to BAME communities. Her presentation will share their work to date including:

- Focus groups – methodology, hurdles, limitations, results
- Iterative process of resource development and testing
- Progress to date and next steps

Twitter: @clairelucas2 @aruknews

Social media and online communities to understand user needs

Deborah Wyatt - Director, talkhealth Partnership

- What benefits can social media and online communities offer to patients and healthcare organisations?
- How can you identify the best communities to listen to and engage with?
- What tools can you use to listen, engage and measure?

12.55 – 13.35 *Lunch*

13.35 – 14.35 **Session 3: Co-production in developing health information**

Groundswell's approach to involving people experiencing homelessness

Kate Bowgett - Director of Advocacy, Groundswell

Groundswell is a charity that delivers a range of innovative projects which put homeless people at the heart of solutions to homelessness. The presentation will highlight three print items that Groundswell has co-produced, that aim to empower people to take steps away from homelessness. It will explore the thinking behind them, the process in which they were created and their impact.

Co-designing MindWell Leeds – A mental health information website: You want to do what?

Alicia Ridout - Deputy Director and Nicola Gallear - Content Manager, MindWell

MindWell is an innovative website, completely co-designed with user groups across the city. From a blank sheet of paper to the current, operational but still emerging site, we will take you on a journey through the ups and downs of collaborative design and content development, accessibility and engagement, creative approaches and linking performance measures.

14.35 – 14.50 *Break*

14.50 – 16.25 Session 4: A practical focus on user involvement methods

Interviews and focus groups – Getting the most out of user involvement

Emily Newsom Davis - Consumer Health Information Specialist

Emily will talk about the fascinating insight you get from two very different approaches to involving users. She will also share some practical steps to get the most out of these processes.

- Focus groups – what are the key techniques to ensure group work creates stimulating debate and allows discussions to evolve usefully?
- 1:1 testing – how careful watching, questioning and discussion can transform how we design and write information.

Voices and their value

Diana Baxter - Head of Services, MS-UK

Diana will share the variety of approaches that MS-UK use to put those affected by MS at the heart of their work. In particular, her presentation will focus on their Virtual Insight Panel which has been instrumental in developing health information.

Using think-aloud protocols to understand public responses to health information

Samuel Smith - Cancer Research UK Postdoctoral Fellow, Leeds Institute of Health Sciences

This practical session will aim to facilitate understanding of the pros and cons of using think-aloud protocols to evaluate and test health information. It will include a working example of how think-aloud interview data can be analysed and understood.

16.30

Close

Professor Theo Raynor - Professor of Pharmacy Practice, Leeds University; Co-Founder and Academic Advisor, Luto Research