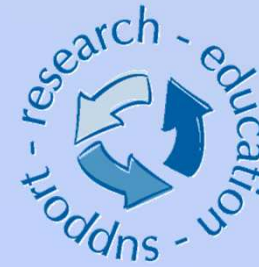


16th Annual Conference of the
National HIV Nurses Association (NHIVNA)



National HIV Nurses Association

Charlie Hughes

Sheffield Teaching Hospitals NHS Foundation Trust

26-27 June 2014- City Hall, Cardiff

Putting patients at the heart of the research process

The Lay Expert Advisory Panel (LEAP)

Charlie Hughes

HIV Clinical Nurse Specialist & Research Nurse



Lay Expert Advisory Panel
South Yorkshire HIV Network

How it all started...

- Sheffield is part of the South Yorkshire HIV Network (SYHIVN)
- Importance and recognition of Patient and Public Involvement (PPI)
- Lay Expert Advisory Panel (LEAP) was launched in March 2012



Who are LEAP?

- People living with HIV
- Caring for someone with HIV
- From a community directly affected by HIV

What is our aim?

To put the patients at the heart of the research process.



What makes LEAP so special?

- Own personal perspectives
- Unique experiences and outlook
- Knowledge and understanding
- Voices heard
- Make a contribution



What does LEAP do?

- Review research proposals
- Trial recruitment advice
- Lay summaries
- Patient information leaflets, consent forms & interview schedules
- Practicalities of participation
- Memberships on steering groups
- Future research topics



Establishing LEAP

1. Steering group
2. Promotional Material
3. Advertising
4. Launch Events
5. Recruitment
6. Training
7. Funding
8. Sustainability



LEAPs Achievements

- 15 members have attended a meeting
- Core group of 6 committed members

Contributions

- 3 National Studies
- 6 Local Studies
- Presentations locally and regionally
- Cited as good practice in regional PPI guidelines & template for other health conditions



Feedback from researchers....

- ‘this type of group is absolutely invaluable for researchers and I will encourage colleagues to come to Sheffield’ Public Health England
- ‘their comments were useful and insightful and certainly improved the patient information leaflets...it was a pleasant experience!’ Sheffield Teaching Hospitals NHS Trust
- ‘LEAP were invaluable, they came with fresh insights that shaped the methodology and analysis of the study’ Sheffield Teaching Hospitals NHS Trust



Feedback from LEAP members....

- ‘LEAP gives me a sense of excitement of what we can achieve’
- ‘a great, productive, full and feisty meeting’
- ‘Our comments on the study design reflect how important we think the study is, it’s good to see our work moving forward’
- ‘Informative discussions where everyone is open and honest in their contributions’
- ‘another vigorous meeting that hopefully reflected our enthusiasm for the projects presented’



Top tips...

1. Advice from Colleagues and Experts
2. Alternative membership
3. Being Organised
4. Communication
5. Commitment from the Facilitator
6. Remain Motivated
7. Ownership (designed new logo)





Lay Expert Advisory Panel

South Yorkshire HIV Network

Thanks to:

Dr Christine Bowman

Dr Jonathan Boote

LEAP Steering Group

STH Research Staff

and most importantly to



Lay Expert Advisory Panel

South Yorkshire HIV Network



Any Questions...