

# How to successfully embed PPI in Research?

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# PPI Champions

- ▶ There are lots of ways of embedding PPI in research
  - ▶ How do you do it on top of existing roles?
- ▶ Staff in the CRF wanted to embed PPI in research teams
- ▶ Based on link nurse model, PPI Champions would:
  - ▶ 8 hours a month
    - ▶ Design and deliver PPI project
  - ▶ Support and training from the PPI team in the CRF
- ▶ To become a PPI Champion



# Induction of PPI Champions

- ▶ Half day induction
  - ▶ Support of CRF Patient Advisory Group
  - ▶ Training – best principles and practice in PPI
  - ▶ Develop the PPI champions' plans and ideas
  - ▶ Offer of further training
    - ▶ Good Practice Guide to Patient and Public Involvement
    - ▶ Plain English

# Setting up the Cardiology Patient Advisory Group

1



Have your say and help us shape research into heart disease

We are a team of researchers working for the University of Edinburgh at the British Heart Foundation Centre for Cardiovascular Science

Our goal is to develop better ways of preventing, diagnosing and treating cardiovascular disease

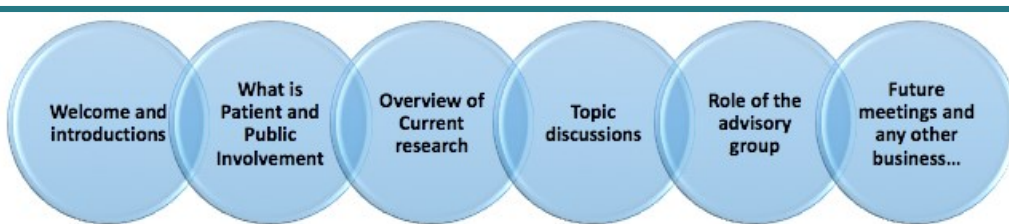
**We want to know what matters to you!**

If you're interested, please get in touch with Lucy (Research Nurse)  
lucy.marshall@ed.ac.uk 0131 242 6428

We developed and distributed recruitment postcards

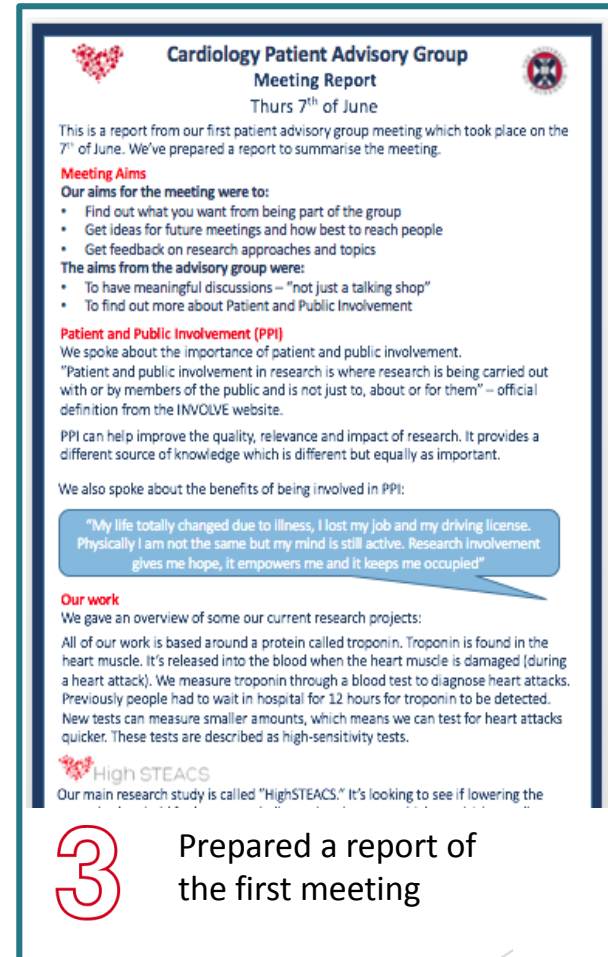
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We held our first meeting in June



3

Prepared a report of the first meeting



**Cardiology Patient Advisory Group Meeting Report**  
Thurs 7<sup>th</sup> of June

This is a report from our first patient advisory group meeting which took place on the 7<sup>th</sup> of June. We've prepared a report to summarise the meeting.

**Meeting Aims**  
Our aims for the meeting were to:

- Find out what you want from being part of the group
- Get ideas for future meetings and how best to reach people
- Get feedback on research approaches and topics

**The aims from the advisory group were:**

- To have meaningful discussions – "not just a talking shop"
- To find out more about Patient and Public Involvement

**Patient and Public Involvement (PPI)**  
We spoke about the importance of patient and public involvement. "Patient and public involvement in research is where research is being carried out with or by members of the public and is not just to, about or for them" – official definition from the INVOLVE website.

PPI can help improve the quality, relevance and impact of research. It provides a different source of knowledge which is different but equally as important.

We also spoke about the benefits of being involved in PPI:

"My life totally changed due to illness, I lost my job and my driving license. Physically I am not the same but my mind is still active. Research involvement gives me hope, it empowers me and it keeps me occupied"

**Our work**  
We gave an overview of some of our current research projects:

All of our work is based around a protein called troponin. Troponin is found in the heart muscle. It's released into the blood when the heart muscle is damaged (during a heart attack). We measure troponin through a blood test to diagnose heart attacks. Previously people had to wait in hospital for 12 hours for troponin to be detected. New tests can measure smaller amounts, which means we can test for heart attacks quicker. These tests are described as high-sensitivity tests.

**High STEACS**  
Our main research study is called "HighSTEACS." It's looking to see if lowering the



# How did it impact on our projects?



# What are our next steps....?

- Continue to recruit some new members
- Prepare an introduction pack for new members
- More training e.g. how to review grant applications
  - perspectives from a PPI member who has reviewed a grant application
  - perspectives from the research team
  - perspectives from the funder (BHF)
- Build links with the clinical team



# Setting up and Running PPI Advisory Group within a CRF

- Devised an action plan and timelines for my project
- Designed Poster/Flyer inviting people to join my group
- Guide document detailing what their role could entail as an Advisory Group member
- 2 hour introductory meeting – 4 new members
- Group discussion focusing on ideas for first task for the group - CRF Patient Leaflet
- Feedback from group members
- Activities since first meeting - training, Buddy scheme, regular contact, Christmas Cards, Informal catch-up & Draft Patient leaflet

# Feedback: what they said

Looking forward to working in the group

Covered all the points that I had expected

Interested to hear the comments of those already involved in PPI

I am still a little bewildered as to what PPI involves and what is required of me

More Informal Catch-ups as so useful

I am intrigued and would like further information and training

This is my first meeting about PPI and it was a very warm and friendly experience



# What was learned?

- ▶ Not easy adapting to change of role – no longer patient/nurse relationship
- ▶ Managing people in a different professional capacity
- ▶ Set Clear Boundaries – terms of reference/agree contract allows mutual respect
- ▶ Recommend to have a least 2 staff members involved
- ▶ Generic PPI Champion contact details rather than individual
- ▶ Don't forget they are volunteers giving up their time

# Summary

- ▶ It has given me a unique opportunity to work in partnership with patients & public while raising awareness of PPI to my colleagues
- ▶ Gained invaluable insight into the benefits that can be obtained as result of involving the wider public in the research process
- ▶ First time doing PPI
  - ▶ a few challenges but
  - ▶ overall a very positive and rewarding experience
- ▶ PPI provided momentum
  - ▶ gave time to support activity and;
  - ▶ support of CRF allowed sharing of ideas and insights

# The Champions

- ▶ 8 PPI Champions
- ▶ PPI groups:
  - ▶ Centre for Dementia Prevention PPI Group
  - ▶ Cardiology Patient Advisory Group
  - ▶ Clinical Research Facility PPI Advisory Group
  - ▶ Colorectal Group is currently recruiting
  - ▶ Plans for Children's CRF PPI Group

# New PPI Courses

- ▶ PPI in Funding Applications
  - ▶ – 4<sup>th</sup> April and 19<sup>th</sup> November (WTCRF)
  - ▶ 24<sup>th</sup> June (RIE)
- ▶ Creating and Running a PPI Group
  - ▶ 14<sup>th</sup> May(WTCRF)
  - ▶ 22<sup>nd</sup> November (RIE)
- ▶ PPI in Clinical trials: Design, Recruitment and Retention
  - ▶ 17<sup>th</sup> June (RIE)
  - ▶ 30<sup>th</sup> October (WTCRF)

On behalf of Kareen, Stacey and all the PPI  
Champions  
Thank you

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