



Introduction

There is a growing body of evidence demonstrating the positive benefits of Patient and Public Involvement (PPI) in clinical research (INVOLVE, 2018). However, delivering high quality PPI takes time and resource, presenting a challenge in any clinical area. The PPI Service in Edinburgh Clinical Research Facility (CRF) wanted to expand its capacity to support the development of PPI across the local research community.

The CRF PPI Service was awarded £15,000 by the Chief Scientist Office to fund bursaries and/or secondment opportunities to deliver PPI projects in Lothian. Alongside the bursary funds awarded annually (£3,000), the PPI service wanted to ensure the remaining £12,000 was used to maximum benefit. 1

The PPI Champion model was developed with the aim to raise awareness across NHS Lothian of the multiple different uses and benefits that PPI can have in clinical research 2. The model enabled time, resource, education and support to be provided to local 'champions' to deliver a PPI project specific to their department/area of research. A further aim was to start a network to share and develop ideas. By inspiring and developing these individuals, the ultimate objective is to increase the capacity of PPI advocates across the region and to cascade their passion and skills to others.

The PPI Champion project is registered as a 'freestyle' project with the NIHR National Standards for Public Involvement.

Recruitment and Induction

Research nursing staff within NHS Lothian were invited to submit a letter of interest. With support from departments and managers, all of the 8 applicants (6 Registered Nurses and 2 Clinical Support Workers) were appointed as the new PPI Champions. Each participating department was provided with funds to backfill posts so individuals could be released from their clinical duties for 8 hours a month for 1 year. 3

All the Champions attended an induction in April run by the Patient Involvement Advisor and members of the PPI Advisory Group. This included education, networking and brainstorming of project ideas. The NIHR National Standards for Public Involvement were introduced as a way to establish good practice, identify successes and challenges and provide a useful framework for their activities. 4

Project development

Following the induction, the PPI Advisor met with each of the Champions to discuss their projects. This included discussions on the best way to proceed and to also identify key measurable objectives to enable post-project evaluation 6.

Each Champion had support available to them from the members of the PPI Advisory Group for the duration of their projects.

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Development and delivery of projects

Patient Ambassadors and public engagement activities at the Centre for Dementia Prevention

To support engagement and recruitment of potential research participants and improve participant experience

Set up of a Colorectal Patient Advisory Group

To support with research design and participant information

Development of a standardised feedback of study results for participants

To improve experience for patients and support future engagement with research

Children's CRF Patient Ambassadors and PPI Advisory Group

To support engagement and recruitment of potential research participants and improve participant experience

Development of the Cardiology Patient Research Panel

To inform and support research design & applications

New WTCRF Patient Advisory Group

Review of participant experience in the Western General Hospital CRF, including a focus on environment and information

7

Embedding and advocating ongoing PPI within local research areas

3

Recruitment of 8 PPI Champions

4

PPI Champion Induction

2

Development of idea

1

CSO Funding for PPI activity

5

Individual project support and mentoring

Perceived benefits

Each of the projects outlined above aims to use PPI to enhance their research practice and the service provided for participants in clinical studies. Perceived benefits of the projects include:

- Improved environments and system processes to enhance participant experience
- Improved public engagement for specific clinical trials with the intention to improve recruitment
- Improved participant information sheets to enhance recruitment and retention in trials
- Involving public in research design, grant and ethics applications
- Giving the public a voice to express what they think new research should focus on
- Development opportunity for staff, increasing satisfaction and staff morale
- Increased awareness of PPI and its benefits and more staff acting as advocates for its use 7

Conclusion

With the support of local managers and funding from the CSO, the PPI service in Edinburgh has been able to increase the breadth of PPI work being undertaken in Lothian through the development of a PPI Champion role. For relatively small investment, there is now a wide variety of projects that could have positive impact on clinical research. The projects are due for completion in April 2019 when the Champions will be excited to share their challenges and successes.

It is hoped that this initiative will promote a continued growth in the awareness and use of PPI in clinical research within NHS Lothian and beyond.

References

INVOLVE (2018) Evidence Library. Available at: <http://www.invo.org.uk/resource-centre/libraries/evidence-library/> [accessed on 22/10/2018]

National Standards for Public Involvement (2018) Available at: https://www.nihr.ac.uk/news-and-events/documents/Public_Involvement_Standards_March%202018_WEB.pdf [accessed on 22/10/2018]



With special thanks to members of the Edinburgh CRF PPI Advisory Group

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