

Patient and Public Involvement in Health Research in Ireland?

A REVIEW OF PROGRESS TO DATE¹

CONFERENCE - TUESDAY, 27th SEPTEMBER 2016

'Involving patients actively in research represents a significant culture change and requires a number of barriers to be addressed including people's attitudes and levels of awareness.'

European Science Foundation, 2010

PPI in Ireland

The recent interest in Ireland in patient and public involvement (PPI) in health research in large part stems from Professor Hannigan's Report 'The Health Research Landscape in Ireland: What Researchers Say' commissioned and published by the MRCG in 2014.² Professor Hannigan, who is now Director of Research, Translation and Innovation in Public Health in England (and has been recently appointed to the board of the Health Research Board in Ireland) concluded in this seminal report in respect of Ireland:

*'The systematic involvement in research of patients or other lay people is not well developed.'*³

One of the 5 key recommendations from the report was the establishment of an Irish Health Research Forum (IHRF) that would include a strong focus on PPI. In making this recommendation Professor Hannigan pointed out that at an international level:

'Many research funders will no longer allocate funding for projects without evidence of an intention to include robust engagement. It is essential that people are trained appropriately for these roles and that researchers are made aware of good practice that they might adopt.'

A number of key developments have taken place since the Hannigan Report. For example, the first meeting of the Irish Health Research Forum (IHRF) took place in late 2014 and by common consent, the first theme of the Forum was PPI.

The outcomes from this Forum are an important contribution to PPI not only at a national but also at an international level and are captured in the IHRF Forum Paper 'Public and Patient Involvement (PPI) in Research' published in April 2015.⁴

The aim of this Forum Paper was to 'assist researchers, policy makers, institutions, the public and patient's to gain a better understanding of what PPI is and how to go about it.' It is useful to restate what PPI is, drawing from the conclusions in this paper:

The role of PPI

PPI describes a whole variety of ways that researchers engage with people for whom their research holds relevance. PPI:

- Plays an important role in ensuring that patients are informed about research that is relevant to them. This is likely to result in increased patient support for research and the improved likelihood of patient involvement in the case of clinical research.
- Is an important step in ensuring that the real life experiences of patients are considered in decision-making processes around research.
- Is key to ensuring that patients and their families have the opportunity to express the questions and needs that matter most to them, which is likely to improve the relevance of research.

1. A paper by Philip Watt and Avril Kennan

2. http://www.mrcg.ie/assets/91/D6C91C07-083D-B049-D8E487D430FE9151_document/MRCG_Research_Report.pdf

3. MRCG p5

4. <http://www.ihrf.ie/#!untitled/cld3>

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- Helps to ensure that studies involving patients are designed to be sensitive to the needs of the study participants.

The support of statutory organisations is also critical to the development of PPI. In this context we welcome the recent commitment in the HRB Strategy:

'Patient and public involvement – people are at the centre of health research. Over the next five years, we will develop initiatives aimed at strengthening the involvement of patients and the public in health research in Ireland.'⁵

PPI as a spectrum



Reproduced from IHRF document on Public and Patient Involvement (PPI) in Research, April 2015.

A key contribution to the international discussion on PPI was to define PPI as a spectrum as opposed to a narrow or prescriptive definition. In this spectrum, the lowest level of participation is 'none' and low levels of participation are defined as the receipt of information about a relevant research without any other participation.

At the higher end of the spectrum PPI is defined in terms of full partnership or indeed commissioning of a research project. There are many excellent examples in Ireland of patient organisations leading the way in PPI in research (see 'Patient organisations and PPI'.)

While some commentators have stated that receiving and disseminating information about a research project is a tokenistic form of participation, it is an aspect of PPI that has an important place. While it is important that we continue to aspire to and indeed succeed in developing a higher level of PPI, there will always be a need to understand and disseminate, in accessible forms, the outcomes of research that will have an impact on a particular patient group or service.

Making the outcomes of research available to patients in an accessible form however is unfortunately rarely done well. To give an example, when a pharmaceutical company issues a press statement on major developments in a new therapy, it is often better to wait until a good journalist rewords the press release into a more accessible form before informing the wider patient group. The best health journalists or informed patient groups will put into plain English what industry often fails to do.

Good Practice example: The series of E Literature reviews produced by the John Hopkins University which are clearly designed for a much wider readership than researchers.⁶

Patient organisations and PPI

Patient organisations, by their nature as a lynchpin between patient, medical and research communities, have long been engaged in PPI. Much current healthcare research wouldn't have been initiated without the drive of patient organisations and they engage in numerous activities to help translate the outcomes of research into patient benefit. Slowly the importance of the patient organisations in this regard is being more formally recognised and valued.

Some Irish examples:

- Fighting Blindness hosts an annual international conference attended by leading eye disease researchers every year, keeping the patient perspective to the forefront of research.
- Cystic Fibrosis Ireland has been a key player in ensuring patient access to the outcomes of research, i.e., innovative, therapeutic drugs by ensuring the patient voice is central to decision making.
- DEBRA Ireland (working through DEBRA International) helps to ensure that patient priorities are central to decision-making on which research to fund, by involving patients as reviewers in the research funding process.
- The Alzheimer Society of Ireland's (ASI) Research Review Committee ensures that people living with dementia are involved in reviewing research requests made to the organisation. Members of the Irish Dementia Working Group are also shaping dementia research, as they are increasingly providing expert advice in both international and national studies.

5. HRB Strategic Plan 2016-2020 p5

6. <http://dkbmed.com/press-release.php?id=17>

Patients overcoming the challenges of PPI

While there are many excellent initiatives in PPI being led by patient groups, there are also challenges for patient groups engaging with health research. In a positive development aimed at over-coming those challenges, an increasing number of patient groups are appointing experts in research or patient advocacy who can formalise and increase the organisation's level of engagement in all aspects of research and care. In some cases these individuals are also patients, parents or carers themselves. This combination of strong, relevant expertise and patient experience can be a very powerful one.

Training and capacity building are also important in overcoming the challenges for patients and patient organisations engaging in research. While in some instances, it is not necessary for patients to have had any previous exposure to the processes of research in order to have valuable input, in other cases a reduced likelihood of tokenism and an increase in the value of patient input can be achieved by appropriate training. In turn, patient organisations sometimes need to become the educators, informing researchers in how to undertake meaningful PPI.

Good practice example: The European Patients Academy (EUPATI) initiatives in which the Irish Platform for Patient Organisations, Science and Industry (IPPOSI) are heavily involved.⁷

PPI in the context of healthcare

It is important to put PPI in research in the wider context of PPI in all aspects of health policy. In recent years there have been a number of significant developments in this regard. These include:

The World Health Organisation (1978) Declaration of Alma-Ata 'People have the right of duty to participate individually and collectively in the planning and implementation of their healthcare'.⁸

In 2008 the Department of Health and Children published 'The National Strategy for Service User Involvement in the Irish Health Service'.⁹ This ambitious strategy usefully identified three levels of participation at an individual level, at a community level and a national level.



Reproduced from the 2008 'The National Strategy for Service User Involvement in the Irish Health Service'.

The three levels of Involvement are:

Individual

On a patient-clinician level: Better health and treatment outcomes; Increased patient satisfaction with care; Increased sense of dignity and self-worth; Empowerment of the patient, leading to greater responsibility for care; Improvements in staff and patient relationships and increased trust; Reduced level of complaints and safer care.

Community

On a community level: Improved policies to address inequalities in health; Services that respond better to the needs of the community; More equitable and inclusive services that help to address social exclusion; Reduced complaints and increased trust.

National

On an organisational level: Ensures policies and service plans are informed, relevant, appropriate and targeted; Cost-effectiveness promoted by delivering better service outcomes; Improved public perception and confidence in the health services; Greater understanding of the links between health, lifestyle and the circumstances in which people live their lives.

7. (<https://www.eupati.eu/>)

8. http://www.who.int/publications/almaata_declaration_en.pdf

9. https://www.hse.ie/eng/services/publications/Your_Service,_Your_Say_Consumer_Affairs/Strategy/Service_User_Involvement.pdf

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The Strategy has also an ambitious and useful definition of involvement which is consistent with the IHRF definition of PPI:

“By ‘involvement’ we mean: ‘A process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change...”

With the possible exception of the Patients Charter most of this service user strategy has gathered dust since it was published. There was no clear implementation or review strategy implemented to ensure its recommendations were taken on board. There was virtually no further reference to the policy in subsequent health policy statements.

Since 2008 PPI in health policy has tended to be piecemeal and top down. The most sustained policy initiative in this context is possibly the National Clinical Programmes, which has included some patient group involvement. As the NCP has not been evaluated it is difficult to comment on the quality of this participation and the impact on services.

Following the Higgins Report, hospitals in Ireland have been reorganised into seven hospital groups a non-statutory administrative basis as follows: (i) RCSI Hospitals (Dublin North East); (ii) Dublin Midlands; (iii) Ireland East; (iv) South/South West; (v) Saolta University Healthcare Group (West/Northwest); (vi) UL Hospital Group (Midwest) and (vii) Children’s Hospital Group. Despite some initial encouragement of non-government bodies to apply to be part

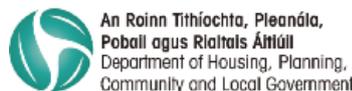
of these new groups, it would appear that very few were actually appointed in the end.

In short, PPI in health research needs to be placed in the broader context of PPI or service user involvement in health policy in Ireland. The 2008 strategy envisaged a framework of different mechanisms by which patients and patient groups would be involved in shaping policy and services in Ireland at an individual, community and at national level. There was no movement on this policy in the wake of a change of government and the economic crisis that has had a cumulative impact on the health services since 2008. The policy needs to be revived.

Conclusion

Since 2014, following the Hannigan Report, there have been some useful green shoots in PPI that have in the main come from patient organisations and in some cases have been responded to positively or in parallel processes by some bodies in the statutory sector and noticeably ignored by others. This paper also looks at some of the challenges for patient groups in relation to resourcing PPI and ways to overcome them, for example appointing personnel with research expertise where possible. There is a need to avoid an overly prescriptive or narrow definitions of PPI. There was widespread consensus arising from the IHRF to consider PPI as a spectrum. The challenge is now to mainstream PPI in all aspects of research and health policy and structures going forward, which will require significant political leadership and a new overall strategy.

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