

# Engaging People with Limited Literacy Skills in Health Service Research

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## Background

Health literacy (HL) refers to the degree to which people can access, understand, appraise and communicate information to engage with the demands of different health contexts in order to promote and maintain good health across the life-course. Evidence shows that limited health literacy has an enormous impact on people's health system utilization, personal health care and health outcomes. Limited health literacy tends to be concentrated among people with poor health status, high healthcare use, low socio-economic status, lower education, and older people. HL responsiveness is defined as the provision of services, programmes and information in ways that promote equitable access and engagement; meet the diverse health literacy needs and preferences of individuals, families, and communities; and support people to participate in decisions regarding their health and wellbeing. Including populations served in the design, implementation and evaluation of health information and services is a key attribute of a HL (responsive) organisation according to the American Institute of Medicine. Similarly, the published WHO draft roadmap (WHO, 2019) has highlighted the importance of organizations to develop their health-literacy-responsive services and information systems and initiatives for targeting vulnerable or disadvantaged groups. HL research is moving from a focus on the individual, to the broader responsiveness of healthcare organisations, with a strong emphasis on the inclusion of the public/patients in research activities. This study will build on existing work of the Galway University Hospital Health Literacy committee to include voices of those with greatest literacy needs.

## Aim

This pilot study is exploring processes that could better engage people with limited literacy skills in health service research with a particular focus on health literacy.

## Objectives

- To raise awareness of health literacy with a group of people with literacy needs
- To identify challenges experienced by people with literacy needs in accessing, understanding and using health information in the health services
- To begin, with people with literacy needs, planning to address the challenges identified
- To develop a protocol for engagement with community groups to raise awareness on health literacy and to co-create practical solutions to challenges identified
- To provide opportunities for direct input of people with literacy needs into health literacy activities of a local hospital
- To conduct a process evaluation of the planning stage.

## Design and methods

A qualitative participatory process was used. Participants were recruited through the Galway Adult Basic Education services (GABES). Three workshops, over six hours. Materials for the workshops were developed by the PI and drew on existing resources from the National Adult Literacy Association, GUH Health Literacy Committee, and the Centers for Disease Control and Prevention. Workshop activities included participants using visual materials to identify both positive and negative aspects of using health services in the context of health literacy. The three workshops were facilitated by the PI and a co-facilitator, Dr Elena Vaughan. Workshop discussions and activity outcomes were recorded on flipcharts, transcribed, and brought back to participants at each workshop.

## Results

Analysis identified several priority areas which were reported to the GUH HL Committee.

## Knowledge Translation

The PPI contributions were included in the health literacy action plan for the GUH Health literacy committee and emphasise supporting the patient's right to understand health information and easier access to health services. The PPI contributions were included in the health literacy action plan for the GUH Health literacy committee and emphasise supporting the patient's right to understand health information and easier access of health services. The PPI feedback also supported the use of the Teach-back method by health care providers and rolling out a campaign to support use of the *Ask Me 3*<sup>®</sup> educational program.

## Dissemination

McKenna, V.B., Sixsmith, J., Byrne, N. (in press). Patient public involvement (PPI) in health literacy research: Engagement of adults with literacy needs in the co-creation of a hospital-based health literacy plan. *Health Expect.*



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### Patient public involvement (PPI) in health literacy research: Engagement of adults with literacy needs in the co-creation of a hospital-based health literacy plan

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