

Redefining policy and interventions from the point of view of the elderly patient with cancer

Abstract: Policymakers want their policy to be effective. An effective policy is one written with the target group, and not about the target group. In the case of elderly cancer patients, a three-fold vulnerability (due to ageing, due to cancer and due to comorbidity) leads to their underrepresentation in research, which in turn translates into few policies that specifically address this group. Current health policy aims to reduce costs, support self-management and encourage active patient role, but how does this fit with what patients need, prefer and are capable of? And, are the conditions in place to make all this possible? This study focuses on the needs of elderly cancer patients and what these policies mean to them.

A qualitative research study is conducted to gain insight in the experiences of elderly cancer patients with healthcare and their daily life. These insights are obtained by means of 30 semi-structured interviews with elderly cancer patients and 20 semistructured interviews with various stakeholders (among others medical professionals, policymakers and caregivers) for a broader perspective. Data collection is still in progress.

Preliminary analysis will focus on how elderly cancer patients attribute meaning and significance to their role in health care and how they cope with illness in daily life. It will explain what is important to these patients, but also why it is important. This knowledge will be used to make recommendations for the development of policies and interventions that fit the needs and daily life, and thereby

are more effective.

[Download poster](#)

Views of Individuals Concerning Research (VOICE): An interpretative phenomenological analysis

Abstract: There is a clear need for research institutions to develop opportunities for patient and public involvement (PPI) within their research themes in order to:

1. provide high quality evidence in areas of importance to patients and the public
2. meet the recommendations of governance guidelines
3. meet the requirements of funding providers.

However, there is a lack of literature describing how PPI advisory groups have been developed, and a dearth of evidence on how development has considered the needs of group members in order to provide meaningful involvement, where such groups are already established.

The aim of the VOICE study was to explore the opinions of patients with uncommon and poorly understood respiratory conditions (chronic cough and aspergillosis) with respect to involvement in clinical research using hermeneutic phenomenology methodology. The main focus of the study was on the interpretation and understanding of motives for involvement or non-involvement in the research process. The

purpose of this was to facilitate the development of a patient advisory group by ensuring opportunities for involvement were aligned with the interests and needs of patients themselves.

We hope the findings of this study will be both interesting and enlightening for INVOLVE delegates to hear and we welcome the opportunity for a discussion around PPI advisory group development.

[Download poster](#)

Using James Lind Alliance methods in setting mesothelioma research priorities

Abstract: The theme of our poster will be James Lind Alliance (JLA) methods, using the example of the Mesothelioma Priority Setting Partnership as an illustration. We will explain how JLA methods invite patients, carers and clinicians to collaborate through steering groups and prioritisation processes and how this adds to the impact of the outcomes. We will cover:

- An overview of JLA priority setting methods
- The funding and motivation of the mesothelioma project
- How patients have been involved with the steering group or represented by organisations which support patients and families
- How patients and carers and patient support groups have been contacted to enable them to suggest initial

questions or be involved in interim prioritisation

- How the above, in collaboration with the views of health professionals, adds to the importance and impact of the outcomes.

We hope that people will learn about JLA methods, particularly relating to the Mesothelioma Priority Setting Partnership and that the poster will raise issues around collaboration of patients, carers and clinicians in setting research priorities.

[Download poster](#)

Patient and public involvement in systematic reviews: Why bother? What's the way forward?

Abstract: Systematic reviews use clear methods to identify and summarise what is known about a health or social care topic. By 'appraising' research, these reviews also tell us how much faith we can have in the knowledge presented. These reviews used to just be about the effectiveness of a drug or medical procedure, but are now used in much broader areas of patient care or experience or to try and understand how services work together.

Traditionally, people doing systematic reviews work at arm's-length from the public. In this presentation, we'll set out reasons why we think there should be more patient and public involvement. We'll also spell out the benefits we think this

involvement could have for both systematic reviewers and members of the public. In particular we suggest that systematic reviews could benefit from the experiential knowledge that members of the public bring while members of the public, by learning about these reviews, will be in a better position to inform their own health care decision making.

But the proof of the pudding comes in the eating, so we'll also share our experience as researchers and parent-carers working together on a systematic review about peer support for parents of disabled children. This will include some of the practicalities, as well as our reflections on what worked well (and not so well!). We'll end by giving our view on how public involvement in systematic reviews can go forward in the future.

[Download poster](#)

The depression puzzle

Abstract: With an estimated one in four people experiencing depression in their lives, solving the puzzle of how to understand and treat this debilitating illness becomes ever more pressing.

In October 2013 members of the Lived Experience Group (LEG) at the Mood Disorders Centre (MDC) of Exeter University hosted a Public Open Day, aimed at both providing information for people experiencing depression and getting them involved with the researchers and research being carried out at the MDC.

The first hurdle was to obtain some funding! This we did by winning a grant of £3,000 from the University of Exeter's

Public Engagement “Catalyst” Seed Fund. Anyone who has ever applied for a grant will know how much work goes into it and we were proud to learn that we were the only group of lay people who were successful in our bid.

The day was organised and run by members of the LEG, with a mixture of presentations, interactive workshops and a more fluid ‘market place’. This format allowed members of the public to meet with researchers, members of LEG, support groups and each other to discuss, in a safe and comfortable environment, their questions about depression, the research being done and how they could influence future work.

We will discuss what we had to do to get the day off the ground, what were the high points and the challenges, what made this event different from others organised by researchers, and how and why we are planning to do it all again!

[Download poster](#)

Understanding patient and public involvement in health services research: From theoretical framework to practical workshop

Abstract: Gibson et al. (2012) recently developed a theoretical framework for understanding and planning patient and public involvement in health services research. This

presentation will discuss the process by which researchers worked collaboratively with three patient and public involvement groups to turn this theory into a practical workshop. In these workshops, individual group members were asked to think about and rate where they thought their group sat along each of four dimensions described in the theoretical framework:

1. Does the group have a strong or a weak voice within its organisation?
2. Do the group members feel that the organisation is listening to the concerns of the public group or do the concerns of the organisation dominate?
3. Are there many or only a few ways to be involved?
4. How likely is it that the organisation will change in response to public involvement?

Participants were also invited to post comments, both positive and negative, to support their ratings.

This poster will also share findings from these workshops, showing how ratings from individual participants can be combined into a visual representation of 'patterns' of involvement within a single group, across different groups, or across a range of activities within an organisation. We will discuss how these diagrams can be used as a starting point for conversations about understanding a group's position within an organisation, what factors might be supporting, or presenting barriers to, public involvement and how these discussions can be used to plan future involvement.

[Download poster](#)

We're all over the place!

Abstract: How can service users based in different locations successfully write and publish their research?

When groups of service users successfully conduct research, they obviously wish to disseminate their results as widely as possible – usually by publishing in a suitable journal. When group members are based over a wide geographical area this may not be easy, as face-to-face meetings can be both difficult to arrange and costly for the participants.

The poster will outline the activities that typically happen before research can be published:

- A decision is made regarding a suitable journal
- A title is chosen
- The work is written up
- The work is typically submitted and edited following peer review.

[Download poster](#)

The role of social media in gathering data: An example from parents of children with the chronic condition

Juvenile Idiopathic Arthritis (JIA)

Abstract:

Key Issue

It is widely recognised that it is important to involve consumers in shaping research priorities and care. Based on consumer led research with parents of children with Juvenile Idiopathic Arthritis (JIA) we show that a variety of methods are needed to obtain a wide collective voice. For example, the role of Facebook, other social media can be useful for reaching parents.

Methods

A single item questionnaire was mailed to three charities and posted as a question on Facebook and a Study database. Respondents were asked to list their top three concerns about their child's condition and care.

200 responses were obtained listing 600 concerns from which 8 themes emerged. These were Medication, Prognosis, Physical impact, Pain, Uveitis, Psychological impact, Social and educational impact, Transition to adult services and Access to care.

Discussion points

We have two central messages.

- The first of these is the importance of obtaining a wide collective view from families in order to inform the provision of care and help shape research priorities.
- Secondly we want to share our experience of the benefits of using social media as an effective and instant means of reaching and involving parents.

[Download poster](#)

Issues, needs and concerns of women with breast cancer in rural areas

Abstract:

Rationale and aims

Conducted by members of Breast Cancer Care's Service User Research Partnership (SURP) this study aimed to identify the needs and concerns of women who had completed treatment for primary breast cancer living in remote and rural (R&R) areas of Scotland.

Methods

In 2013, a mixed method study was undertaken involving a survey of supportive care needs with women living in R&R areas of Scotland. Semi-structured in-depth telephone interviews with 9 of the women reporting the greatest needs followed. Interviews were conducted by SURP members located in Scotland, with personal experience of breast cancer.

Results

The key themes that arose from the qualitative findings were linked to women's experiences of a lack of appropriate information about their diagnosis and treatment. There was also discussion of systemic problems such as long waits for diagnosis and extraneous issues including difficulties travelling to appointments.

Conclusions and recommendations

Findings suggest that women living in R&R areas of Scotland do have issues resulting from their geographical location and distance to and from their treatment centre. We recommend that

a 1-stop service is offered to these women – linking together all aspects of treatment thus minimising the patient's travelling time and disruption to home life. We hope that people will learn more about the needs of women living in rural and remote areas but also the impact it has had on the learning and development of the researchers in the context of exploring the needs of those diagnosed with breast cancer when the researchers have had personal experience of this.

[Download poster](#)

The changing landscape of a clinical trials unit: Working towards making PPI part of the culture of our organisation

Abstract: The Medical Research Council MRC Clinical Trials Unit (MRC CTU) at University College London (UCL) develops, runs and reports clinical trials and other research studies in areas including cancer, HIV and other infectious diseases. The MRC CTU Patient and Public Involvement (PPI) Group, which includes staff and patient representatives as members, has been working towards increasing the profile of PPI across the Unit to make PPI an integral part of our research culture.

We want to share the breadth of our recent experiences and achievements including:

- Developing and implementing a PPI policy at MRC CTU

- How we support our researchers in their PPI activities
- How we support our patient representatives in their research activities
- How we ensure PPI in all of our clinical studies.

We will also highlight some of our individual activities including:

- Improving patient information sheets for our clinical trials: a joint project between staff and patients
- Collecting case studies of PPI in our clinical research: sharing the learning using examples of impact
- The development of some short films about PPI in clinical trials.

We will discuss issues that we have experienced such as the challenges of supporting PPI across a broad spectrum of activities and how we have tried to ensure consistent standards across all of our work. Our presentation will be codesigned and co-delivered by our staff and our patient representatives.

[Download poster](#)

Stronger together: Collective endeavours of a cleft and research organisation to promote the role of young

people affected by a cleft in research

Abstract: The Cleft Lip and Palate Association (CLAPA) is a national charity that supports families and individuals affected by a cleft. It has been working closely with the Cleft Collective over the past two years to promote the active involvement of its members in research. The Cleft Collective is the world's largest cleft lip and palate research programme, with teams based in Bristol and Manchester. One group that has played an on-going role in this developing work is the charity's Children and Young People's Council (CYPC).

We are in the process of carrying out a consultation of young people's views and attitudes in shaping research on cleft. This will involve a focused discussion with members of the CYPC about what has happened so far and ways to improve this process in the future. We will explore what research means to this group, barriers and enablers to involving young people as patient and public involvement (PPI) partners and what these individuals might want to realise personally and more globally from undertaking such a role. We will report on results of this consultation, which we hope will prove useful for fellow delegates at the conference striving to engage young people in a PPI capacity. We anticipate it will raise issues that others have faced or considered when working with this age group in study development, production and dissemination.

[Download poster](#)

Future directions for learning and development for researchers and patient and public involvement representatives in the East of England

Abstract: Despite the availability of patient and public involvement (PPI) in research training courses and resources, both researchers and PPI representatives (PPIRs) cite training as an unmet need in the East of England (EoE). We therefore undertook a survey of researchers and PPIRs in the EoE to find out what participants thought were the learning and development needs for:

1. researchers
2. PPIRs
3. the participant and
4. how these needs could be met.

Seventy-nine people answered the survey (74.7% researchers and 25.3% PPIRs). Some researchers misunderstood PPI to mean participation while some PPIRs thought it referred to changing NHS services. Many recognised that much training had already taken place in the EoE and felt the training available met the needs in the region. Therefore some felt that the focus should be on improving the publicity of resources, organisations and networking mechanisms that were already in place. On the other hand some responses highlighted the fact that training needs are individualised and it is difficult to meet these by using a 'one size fits all' approach. Areas of wide consensus between the groups centred on the need for training in PPI

best practices, practically carrying out PPI roles and basic research and methods training for PPIRs. Many preferred physical events for training over virtual and printed mediums. We hope to utilise more detailed results from the survey to stimulate discussion about future directions for PPI learning and development for researchers and PPIRs.

[Download poster](#)