Picker Institute Europe

Picker Institute Europe is an international charity dedicated to ensuring a positive experience of health and social care is everyone’s experience. We are here to:

- Influence policy and practice so that health and social care systems are always centred around people’s needs and preferences.
- Inspire the delivery of the highest quality care, developing tools and services which enable all experiences to be better understood.
- Empower those working in health and social care to improve experiences by effectively measuring, and acting upon, people’s feedback.

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Summary

This Executive Briefing reports on the outcomes of an international research seminar, which took place at Rewley House, Oxford on 10th and 11th July 2014. It summarises the issues that were discussed in relation to patient centred research, and related attempts to improve services, across Europe. It then describes some of the key elements of an emerging research strategy that can inform future developments in the field. It should be of interest to a range of stakeholders including researchers, practitioners, policy makers and patient and consumer groups. The aim is to stimulate further, well targeted, research and to leverage funding for international research that can inform the provision of patient centred care in European countries. Comments are welcomed (contact details are provided at the end). A list of participants is contained in Annex B; however, the Picker Institute takes responsibility for the accuracy of this briefing.

Background: The Strategic Seminar

Early in 2014, discussions between senior staff at Picker Institute Europe, Picker Institut Deutschland and the Institute for Research in Operative Medicine at Witten/Herdecke University, identified the need for a more strategic approach to patient centred research in Europe. It was agreed that the best way to make progress was to engage in a wider discussion with key researchers to see if common themes and priorities could be identified leading to more effective cross-organisational working in Europe. It was agreed that Dr Andrew McCulloch, the Chief Executive of the Picker Institute, would host an international seminar to address this and that this would be co-Chaired by Professor Edmund Neugebauer of Witten/Herdecke University.

The two day seminar took place in Oxford, England, in July 2014 with representatives from Spain, The Netherlands, England, Wales and Germany. In addition delegates were invited from Scotland, Norway, France and Italy and were unable to attend, but some indicated they were keen to engage with strategy development in the future. Delegates included researchers, managers, practitioners and service users although they were invited because of their interest and expertise in patient centred research and not as “representatives”. The seminar consisted of brief presentations of current research interests by all delegates and then intensive discussion of the emerging themes and trends. It was agreed that a summary document would be produced for wider dissemination. It was also agreed that there was potential for future meetings in subsequent years, assuming these were goal directed and went beyond information exchange to focus on collaboration. In doing this the group were keen to widen the net to involve more health jurisdictions and agencies. This executive summary provides an agreed summary of the issues discussed at and findings of the seminar.
Current themes in Patient Centred research in Europe

The following key themes were identified by delegates as being of current interest:

Identifying the research questions and involving patients in research

- We need to have a clear understanding of the different levels at which patient engagement can operate and in order to have engaged, expert, patients we need to understand what mechanisms are needed to translate experience into expertise and expertise into sustainable action at each level (i.e. knowledge transfer);
- Carers require differentiation from patients in terms of their experience of the care of their loved one and their involvement in that care. Additionally patients with different conditions may also require differentiation so that engagement methods are suited to their condition and needs;
- In building a research strategy attention needs to be paid to engaging patients in research. This needs to start with focus group discussions and/or in-depth interviews and build through patient involvement on advisory groups, patient led research strategies and engagement with patient organisations.

Figure 1
Clarifying the concepts

- There is a need to develop a better understanding of what patient centred care means in practice so that we have a definition that can be operationalised and which can drive further research;

- There is a need to consider whether the concepts of PREMs and PROMs are helpful or whether a re-focus on patient definitions of quality is required;

**Figure 2 Source: Dr Sian Rees**

Health Literacy

- Health literacy is key to empowerment and the ability to be a partner in the care process. Limited attempts have been made to address health literacy so far in Europe. Patient empowerment needs to be supported by tools such as information and decision aids. Given that there are at least 350 shared decision aids worldwide a strategic approach would be needed to promoting such tools in Europe. However, tools are not enough in themselves, there have to be clear outcomes for patients and patients have to be able and enabled to use tools. Options grids have been shown to be a good tool within this context. In developing these products we need to understand the implementation phase and what works in implementation;

- In looking at health literacy we need to understand that it is a composite variable with a number of components including cognitive ability, locus of control, knowledge, attitudes and motivation. It needs to be clearly defined it is to be of use in a research context and existing definitions should be considered (Abel and Bruhin (2003) and Kickbusch et al (2005).

**Figure 3**

Health “literacy”:
Shared Decision Making

- Shared Decision Making has proved a valuable concept in the past but also has significant risks associated with it:
  
  i. Doctors think they already do SDM so it is difficult to implement;
  
  ii. There is a need to draw a distinction between SDM which is a rather rational process and emotional support which patients value as much or in some cases more;
  
  iii. There are multiple communication channels between clinicians and patients not all of which are captured in the SDM model;
  
  iv. SDM happens often at the interface between patient and team(s) not in a dyadic relationship;
  
  v. Trust is core to the model but is relatively intangible;
  
  vi. SDM needs to take account of legal, rights based and bureaucratic requirements around consent to treatment, capacity and care planning – which cannot all be “shared” because they lie with one party such as the patient or the health care provider.

*Figure 4*
Data collection

- National patient surveys have been a step forward in those countries that have implemented them; however, they have not been that useful for driving improvement either in the UK or the Netherlands. There can be conflicts when the data is collected for regulatory purposes with the improvement agenda, and the latter generally requires more granular data;

- Patients have a range of criteria that they use to make choices in health care including decisions about providers, treatments and condition management. Data and quality controlled information platforms are needed that bring together different qualitative and quantitative information;

- A lot of patient experience data that has been collected in some countries for regulatory or improvement purposes has not been exploited for research purposes;

- We need to collect data that is person centred – so that it is relevant to the person’s whole life. It should not be structured around the unit or the bureaucracy otherwise we will reinforce service centred approaches;

- We need to understand whether compliance is a valid outcome. If patients are empowered they may choose other alternatives. It is important that compliance is only seen as a valid outcome in the context of truly informed consent;

- More generally, we need to understand what is meant by a “good” outcome. For shared decision making we need to consider and measure the quality of decisions made: is the right patient being matched to the right solution? This will require the use of both objective and subjective measures to establish the quality of the process and the decision.

Organisational development/implementation

- It would be valuable to revisit the Salzburg statement (Annex A) with a particular emphasis on how these principles can become embedded in policy;

- There is a problem at the meso and macro levels with patient involvement in practice showing impact on policy. We need to understand the mechanisms by which patients can be effectively involved at these levels;

- There is a parallel issue of service improvement often being effective at small unit level and then not being scaled up to organisational level;

- A key issue is real world implementation of SDM once the concept has been clarified;

- The organisational level is a key level of analysis when considering implementation. It has a significant impact at team and individual levels. Teams need to demonstrate how they are improving quality and organisations need to demonstrate and interest in and organisational learning from what teams are doing;
There are also benign spiral effects to be considered in relation to implementation. For example, once you start involving patients more, their interest in and the sustainability of involvement increases, reinforcing further involvement;

Clinical resistance to the patient centred agenda is still strong in many countries. We need to understand the barriers and the opportunities as well as the differences between countries;

There is a number of dimensions to this resistance:

i. Some professionals, for example, often do not want to communicate and do not see it as part of their required expertise;

ii. Improving patient experience can sometimes be over-simplified into a criticism of clinicians but this is a poor starting point;

iii. Clinicians and researchers need to co-produce research and evaluation – clinicians do not like to be cast as passive subjects;

iv. Data is key to getting clinicians onside: both hard data and patient stories;

v. We need to learn from the human factors story in the air industry.

Finally, in addressing key issues in implementation it was considered essential to ask the right questions about each stage of the process.

**Figure 5**

<table>
<thead>
<tr>
<th>Level/Nature of Engagement</th>
<th>Micro/Individual</th>
<th>Meso/Unit Agency, Locality</th>
<th>Macro/Region Government, Nationwide Provider or Commissioner</th>
</tr>
</thead>
<tbody>
<tr>
<td>Receipt of Information</td>
<td>Patient reads decision tool or information leaflet</td>
<td>Unit implements decision tool or designs information product</td>
<td>Information tool is national mandated</td>
</tr>
<tr>
<td>Engagement</td>
<td>Patient actively engages in care</td>
<td>Patients engage with units e.g. give feedback, attend meetings</td>
<td>Patients engage with policy</td>
</tr>
<tr>
<td>Co-production</td>
<td>Patient self-manages and co-produces own care</td>
<td>Patients co-produce health care activity, service design, local policy</td>
<td>Patients co-produce policy</td>
</tr>
</tbody>
</table>
Outcomes from the seminar

Broadly speaking there were three main outcomes from the seminar:

(a) An agreement to work together in the future on a range of opportunities;
(b) Some degree of consensus on the core concepts, although this requires further refinement and indeed there will always be the need for multiple models each shedding different light on the patient experience agenda;
(c) Agreement on some of the key elements for an emerging research strategy on patient experience and crucially implementation in terms of sensitising and improving services and policy.

a) Working together

The group considered that there would be value in establishing a strategic network of researchers in Europe that could:

- Share knowledge and keep each other informed about projects;
- Create opportunities for further research on core strategic themes;
- Collaborate on such research and secure multi-site research funding;
- Translate research into policy, communications and action – in other words to focus on implementation;
- Bring research to patients and having a dialogue with them;
- Develop guidelines;
- Develop a virtual community of practice for sharing learning and experience with regard to the implementation of patient centred care;
- Support the empowerment of patients;
- Advocate for relevant policies based on the evidence obtained;
- Set the research and implementation agenda.

It is proposed that there is a meeting, probably in Germany in Spring 2015, to review progress, refine the agenda and where possible agree specific actions. This will provide an opportunity to draw in those people and agencies who could not attend in July 2014.

b) Core concepts and frameworks

The group discussed a number of concepts and frameworks including:
- The ladder/grid of involvement (Refer to Figure 1)
- Patient centred care (Refer to Figure 2 and Figure 4)
- Evidence based medicine (See Figure 7)
- Quality (See Figure 8)
- Health literacy (Refer to Figure 3)
- The implementation cycle (See Figure 9)

*Figure 7 adapted from Prof Neugebauer’s presentation*
All these were felt to be helpful to a greater or lesser extent – but understanding what we mean by quality and patient centred care is fundamental.

The group had a discussion about the important concept of evidence based medicine which at its best includes a strong patient perspective. However, there were important reservations:

- Evidence based medicine does not normally take account of cultural issues;
- It focuses on what we already know and does not address contextual issues such as organisational structures and policies;
- Patients see it as a medical perspective;
- It could be reductionist and as such lacks wider intellectual rigour in terms of integration and multiple forms of evidence, and it must recognise that health is part of a bigger picture of life, family, community etc;
- We need to influence the dynamic between the patient and the implementation process, which is linked to patient engagement.

This discussion led the group to conclude that it will be necessary to construct an integrative model which balances the priority placed on health outcomes with other factors. The concept of evidence based medicine needs to be integrated with patient centred care, they cannot work separately. In discussing their view of patient centred care, the group favoured a model which centred on the overlap between the individual, the organisation and the system. It was also noted that patient experience is insufficient to define quality which includes safety and effectiveness. It’s value is also dependent on the methodology used to collect patient experience data.

c) Research priorities
At the end of the seminar, the group reflected on key priorities which might form the basis of a research strategy. However, it was noted that as implementation is a key issue, the strategy needed to be more about research and development into practice. 5 key priorities were identified and agreed:

1. **Using existing data**
   There was strong interest in mapping and exploiting the existing qualitative and quantitative data that already exists. In doing this we would need to clarify:
   - What we want to achieve in using these data;
   - Which organisations or stakeholders might be interested in the findings;
   - What they want from the data and how they might use them to improve quality.

2. **Focus on specific disease groups, patient groups or communities**
   It was felt that there was a clear need for some specific focused work on groups such as:
   - Integrated care for co-morbid long term conditions. There is currently a limited literature in this area which focuses only on certain conditions such as diabetes. Yet the more long term life limiting conditions someone has, the worse their experience can be, the more they use expensive hospital care, and the less opportunity they have to self-manage. There is evidence that when a patient has a certain number of conditions it is no longer possible for them to absorb all information and follow all the professional advice. Therefore we may need to develop new care pathways which accord with patient’s key priorities;
   - Vulnerable patients and hard to reach groups with conditions such as dementia, learning disabilities and other cognitive impairments, and patients with social care needs. There is a particular need to look at the meaning of health literacy for such groups and how they can be empowered. There is a need to build skills and self-confidence. We need to build specific opportunities for engagement tailored to people’s needs. There is funding available for research with such groups and a clear link to inequalities in health;
   - Offenders especially those in the penal system;
   - Specific geographic communities. Healthcare transcends individuals and individual service and might best be studied at this level. We also need to understand resilient communities and how communities can support individual health and why some do not.

3. **Patient information and support tools.**
   The group considered that there were six key questions sitting within this topic:
   - (i) How do we ensure patients get the right information?
   - (ii) Where should patients look for information? Are there alternatives to the internet for information delivery?
   - (iii) Option grids provide information and can be aligned for inclusion in guidelines such as NICE guidelines (in England) but are they readily accessible? It was
noted that they are only relevant for specific decision points along the journey and that we might have to structure information for complex care pathways. They also need to be integrated into policy and implementation structures.

(iv) Following on from this we need to understand how best to develop roadmaps for patients and how to direct them to the best information. Questions within this include whether we should have European level accreditation for websites? Accreditation needs to be explored as people do not take much notice of accreditation and often useful sites are not accredited. We need to understand what is realistic and what the other options are to help ensure patients get quality information.

(v) What is the purpose of the information? There is little value in information for information’s sake. The purpose is to improve patient care and outcomes by addressing the power imbalance. We need to increase patient confidence rather than confusion. Information is a small step towards this goal so perhaps there needs to be a shift towards education. This relates to the relationship between information in different forms and the wider issue of health literacy. How best can information support the development of health literacy?

(vi) How do patients become “expert” patients? What is their experience and their journey?

4. Using patients in experiential learning for healthcare staff
   This is a general issue which requires further R&D input. Specifically, for example, we need to understand the value of using patients as mentors for medical students and other trainees. Experiential learning is a powerful technique which is still under-utilised.

5. Cross cultural, cross system studies
   It was felt that there could be great value in multi-site research, especially in areas where we already expect that there will be cultural and system variation e.g. self-management. There were a lot of natural experiments going on in different health jurisdictions in Europe that could be studied. It would be important to involve areas such as mental health care in SE Europe, which had not yet been touched by the patient experience agenda.

Conclusion

The seminar was felt to be extremely useful both in terms of information exchange and of building a consensus about the next steps. The degree of consensus was very high given the different experiences, countries and disciplines of the people present. The outcomes now need to be translated into an action plan, at least in the areas in which those present can exercise some leverage. The key issues for implementation work have been shown below in italics as a supplement to the Salzburg Statement.

If you have any comments on this paper or can help in any way please contact Dr Andrew McCulloch at Picker Institute Europe Andrew.McCulloch@PickerEurope.ac.uk or at Picker Institute Europe, Buxton Court, 3 West Way, OXFORD OX2 0JB. The Picker Institute is grateful to all those involved for their time and commitment.
Annex A: The Salzburg Statement on Shared Decision Making

In December 2010, 58 people from 18 countries attended a Salzburg Global Seminar to consider the role patients can and should play in healthcare decisions. This meeting resulted in a statement that calls on patients and clinicians to work together to be co-producers of health.

“We call on clinicians to:

- Recognise that they have an ethical imperative to share important decisions with patients
- Stimulate a two-way flow of information and encourage patients to ask questions, explain their circumstances, and express their personal preferences
- Provide accurate information about options and the uncertainties, benefits, and harms of treatment in line with best practice for risk communication
- Tailor information to individual patient needs and allow them sufficient time to consider their options
- Acknowledge that most decisions do not have to be taken immediately, and give patients and their families the resources and help to reach decisions.

We call on clinicians, researchers, editors, journalists, and others to:

- Ensure that the information they provide is clear, evidence-based, and up to date and that conflicts of interest are declared.

We call on patients to:

- Speak up about their concerns, questions, and what's important to them
- Recognise that they have a right to be equal participants in their care
- Seek and use high-quality health information.

We call on policymakers to:

- Adopt policies that encourage shared decision making, including its measurement, as a stimulus for improvement
- Amend informed consent laws to support the development of skills and tools for shared decision making.

Why?

Much of the care patients receive is based on the ability and readiness of individual clinicians to provide it, rather than on widely agreed standards of best practice or patients preferences for treatment.
Clinicians are often slow to recognise the extent to which patients’ wish to be involved in understanding their health problems, in knowing the options available to them, and in making decisions that take account of their personal preferences.

Many patients and their families find it difficult to take an active part in healthcare decisions. Some lack the confidence to question health professionals. Many have only a limited understanding about health and its determinants and do not know where to find information that is clear, trustworthy, and easy to understand.”


Supplementary statement from the Oxford Seminar

“We call on researchers, research and education organisations and health care agencies to

1. Map and exploit existing data sources on patient centred care
2. Undertake focused work on specific care pathways and patient groups where patient centred care is poorly developed
3. Support the provision of better patient information through a variety of channels. Accreditation of information needs to be considered as part of a coherent strategy to deliver better information to patients
4. Healthcare staff need systematic opportunities to learn from patients in both basic and continuing education
5. Undertake cross-country, cross system and cross cultural work to understand the common parameters of patient experience and subsequent quality improvement.”
Annex B: Participants at the Seminar

- Dr Angela Coulter, Senior Research Scientist, Health Services Research Unit, Nuffield Department of Population Health, University of Oxford
- Dr David Crepaz-Keay, Head of Empowerment and Social Inclusion, The Mental Health Foundation, UK
- Mr Chris Graham, Director of Research and Policy, Picker Institute Europe
- Dr Amy Lloyd, Shared Decision Making Facilitator, Institute of Primary Care and Public Health, Cardiff University School of Medicine, Wales
- Dr Andrew McCulloch, CEO, Picker Institute Europe Co-Chair
- Professor Edmund Neugebauer, Director of the Institute for Research in Operative Medicine, School of Medicine Witten/Herdecke University, Germany Co-Chair
- Dr Lilisbeth Perestelo Perez, Clinical Psychologist, Evaluation Unit, Canary Islands Health Service
- Dr Jany Rademakers, Head of Research Department, Netherlands Institute of Health Services Research (NIVEL)
- Dr Sian Rees, Director, University of Oxford Health Experiences Institute, Nuffield Department of Primary Care Health Sciences, University of Oxford
- Dr Ian Seccombe, formerly NHS Patient Surveys Lead, Care Quality Commission, England
- Prof. Rosa Sunol, Director, Avedis Donabedian Institute – Universitat Autonoma de Barcelona and REDISSEC (Red de Investigacion en Servicios de Salud end Enfermedades Cronicas), Spain

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