Measuring the impact of patient and public involvement in the JLA Kidney Transplant PSP

Contents

Overview and summary of outcomes

PiiAF (Public Involvement Impact Assessment Framework) has been produced to help researchers assess the impacts of involving members of the public[1] in their research.

PiiAF was trialled here within a James Lind Alliance Priority Setting Partnership (JLA PSP). The project aims to:

- pilot PiiAF itself as a PI assessment tool, noting what works well and less well within the process

- use PiiAF to identify and complete an assessment of the impact of PI within the JLA PSP.

A subgroup of PSP members agreed to work through Phases 1 and 2 of PiiAF (see Appendices). Also see *Values Exercise* (p5) and *Impacts Exercise* (p7).

Piloting PiiAF:

Although it was not always straightforward to get the concept of PIIAF across, Phase 1 provided a clear way for the group to focus on its values and motivations, which was welcomed by participants.

However, the process of identifying impact assessment projects had the potential to be heavily influenced by those with research experience. It was not always clear how the values suggested by the group connected with the assessment projects they wanted to carry out. A fuller description can be found in *Using PIIAF Within The JLA Framework* (p3).

Identifying impact assessment projects:

Four potential research projects were identified by this subgroup and presented to the full steering group for ranking. Of these four, the group chose an assessment of the impact of different types of survey participant on the types of suggested treatment priorities. See *Next Steps* (p.8).

---

[1] in the context of this report references to "public" involvement reflect that of patients and carers.

Using PIIAF Within The JLA Framework

Initial attempts to get a JLA PSP to sign up to trialling PiiAF (spring 2014) were not successful; the Kidney Transplant PSP Steering Group eventually agreed to take part, as discussed below.

Explaining the concept

Getting the concept of PiiAF across to people was not straightforward. While this might not be so difficult with groups who already have an identity and an understanding of how they normally work together, PiiAF did not lend itself well to the early parts of the JLA process. Potential participants on the PSP steering groups were new to each other and to the JLA, and thus many were already struggling to grasp how the JLA PSPs work and how they might contribute to that. Adding the concept of PiiAF to the mix seemed to lead to information overload, and the first PSP where it was attempted did not in the end take the project on.

Even people who are used to research can struggle with the idea of a deciding on a research project inside a project about research decisions; this is not limited to PiiAF. In our first subgroup meeting of the JLA kidney PSP, it was not always easy to get participants to separate "what needs to be researched (in kidney disease)" from "what needs to be researched (within the PPI of the JLA)".

Is it relevant?

In general, discussion in the subgroup kept getting pulled away from PiiAF to key areas of concern in kidney research and treatment. This suggests that these areas were of much higher priority to participants than the PiiAF aims. This could be a feature of the fact that PiiAF was somewhat imposed on this JLA PSP rather than emerging from a real need to explore the impact of the PPI part of the process. It could also be a group dynamics issue – it was not entirely clear who should be leading the meeting, the existing chair, the 'PiiAF researcher', the PiiAF representative, or the JLA advisor. Thus it was not always easy to keep discussion on track.

PIIAF values exercise

The values exercise in Phase 1 led to some good discussions and was welcomed by all members of the group as interesting. As the carer representative put it, "it does clarify the mind, thinking about it like this." Among the points captured:
- the fact that the JLA advisor had different values when she considered her personal feelings about PPI versus the values of the JLA itself
- People noted that their values might change according to the situation, and that they might prioritise different values at different times and places.
- The clinician representative's values were rather different from everyone else's. A second clinician due did not attend. The possibility of different outcomes based on who attends raises issues around the representativeness of the subgroup.

Connecting values and impacts

It was not entirely clear how the values exercise linked with the impacts people wanted to explore. Again, at this point the discussion 'bled' back into talking about researching kidney disease rather than researching PI impact. There was no explicit connection between the ideas people came up with and the values that the group had agreed on. The values exercise might, however, be something that could be referred back to when final decisions need to be made about what to research, if consensus were hard to reach.

Language and comfort with research concepts

It was more difficult for those who had limited experience of research to contribute usefully compared with those who were familiar with what is or is not normally considered feasible. Some research concepts and methods are harder to explain from scratch than others; for example, when ethnography was mentioned, one participant commented "that [word] sounds complicated" and the idea was somewhat side-lined as a result. Those who were used to research design tended to dominate the discussion, purely because they were used to thinking in this way.

Timing issues

Getting JLA steering group members together is already a challenge, since they are often geographically far apart and have numerous demands on their time. It was felt that it would be too onerous to get the entire steering group together to discuss PiiAF, for example, and teleconference agendas were already quite tight. Adaptations were required before the Kidney Transplant PSP Steering Group could timetable PiiAF work.

Key factors for success

The role of the Steering Group Lead in this process was key in terms of legitimising the extra work involved in PiiAF, and scheduling times to progress it. In the Kidney Transplant PSP, the SG Lead (in this case, a clinician) contributed enthusiasm and commitment to the PiiAF process, as well as finding venues for meetings and circulating information to the wider group.

PiiAF's flexibility was also key; in this case, a subgroup of the main steering group was convened to take the process forward, comprising patient, carer and clinician representatives as well as a JLA Advisor.

PIIAF Phase 1

Meeting at the Royal College of Surgeons, 2 July 2014

Sub group of Kidney PSP steering group:

Leanne Metcalf (JLA representative and JLA Advisor), Simon Knight (clinician representative and SG Lead), Angela Beale (patient representative), William Beale (carer representative)

Support:

Michelle Collins (PiiAF), Rosamund Snow (researcher)

The meeting used phase 1 of PiiAF to identify the key values the group held in common about patient and public involvement, and explore the impacts that they wanted to assess. This included an exploration of factors that might shape those impacts including values (personal and organisational), the public involvement approach used in the JLA process, research focus and design and practical issues.

Values Exercise

Core values identified and agreed on by the subgroup for patient and public involvement:

Effectiveness
Public involvement has an effect on research and implementation
Voted for by patient, carer, and JLA reps

Accountability/Transparency
Public involvement involves clarifying the relationship between the research and wider society
Voted for by clinician and JLA reps

Partnership/Equality
Respecting diversity, values, skills, knowledge, and experience in mutually beneficial public involvement process
Voted for by patient and JLA reps

Respect/Trust
Respecting diversity, values, skills, knowledge, and experience in mutually beneficial public involvement processes
Voted for by patient and carer reps

Role of patient and public involvement (PPI) in the JLA process

Stage of process	Level of public involvement	Method of public involvement	Specific public involvement activities
Initial enquiry	None	N/A	N/A
Steering group convened	Co-control	Oversight Decision Making	Meetings Teleconferences

Stage of process	Level of public involvement	Method of public involvement	Specific public involvement activities
Initial awareness meeting (optional)	N/A for this PSP	N/A	N/A
Identification of uncertainties	Consultation	Survey Focus groups (?)	Online Survey Paper based survey
Sifting	Co-control	Peer review Challenge	Meetings Teleconferences Emails
Checking	Co-control	Peer review Challenge	Meetings Teleconferences Emails
Presentation of uncertainties	Co-control	Peer review Challenge	Meetings Teleconferences Emails
Interim priority setting	Consultation	Survey Focus groups?	Online survey Paper-based survey?
Analysis	Co-control	Decision-making	Meetings Teleconferences Emails
Identify top 10	Collaboration	Workshop	Small group work Plenary sessions
Next steps	Collaboration	Dissemination Quality assurance	Checking data Data entry
Communications	Co-control	Dissemination	Workshop Preparation of journal article

PIIAF Phase 2

Teleconference, 14 July 2014
Present: Full Steering Group (see http://www.transplantpsp.org/kidney/who.php for details).
Support:
Rosamund Snow (PiiAF researcher)

Impacts Exercise

The subgroup identified four areas where they felt the impact of PPI could be explored, which were then presented to the general Steering Group and discussed in teleconference. They are listed here in the order of importance to the Steering Group.

1. **Impact of different types of survey participant (patient/carer/clinician and subgroups of these) on suggested treatment priorities**.
   Discussed: the possibility of looking at the full range of suggestions made by survey respondents, and comparing them according to their demographics. The survey already asks for information about whether respondents are patients, carers, and clinicians, and also asks a number of other questions (such as how long the patient has been waiting for a transplant). This information could be used to compare responses of patients/carers with clinicians, different types of clinician with each other, patients with carers, and patients with different illness experiences (for example, those who have had dialysis for more than five years with those who have had it for less than five years). A secondary part of this project could be looking at the final collaborative top ten to see where the suggestions originated.

2. **Impact of patient/carer involvement on what counts as a treatment uncertainty**
   Discussed: the possibility of looking at the way different members of the steering group view the range of suggestions that come in from the initial survey. In every JLA PSP, some suggestions come in during the survey which are rejected by the steering group because they are not a treatment uncertainty or do not come within the scope of the PSP. The exact protocol for doing this is not laid down by the JLA, and so may differ from PSP to PSP. In the suggested research, it was suggested that a clinician to identify a list of these for rejection, and members of the steering group to consider whether they agree with this list. If there are differences between the questions the clinicians reject/accept and those the patient/carer representatives reject/accept, this could be recorded.
   NB: This project was ranked equally with the following one, the Steering Group agreeing to vote on their preference between them if required.

3. **Impact of JLA patient involvement process on funding decisions**
   Discussed: the possibility of measuring whether priorities set by the JLA PSP, with its

PPI focus, were more likely to be picked up by government and charity funders than other priorities with no PPI credentials. This might include looking at the projects funded in kidney transplant in previous years and comparing them with those funded in the years immediately following the publication of this PSP's top ten priorities.

NB: This project was ranked equally with the previous one, the Steering Group agreeing to vote on their preference if required.

4. **Impact of patient/carer involvement in general within the JLA steering group**
   Discussed: the possibility of looking at the patient and carer contribution to collaborative decisions made by the group (for example, decisions about how the survey is worded, who to send it to, and so on). NB there is a disadvantage with this option in that the first few steps of the process have already taken place, but observations and interviews could be used to focus on a later part of the process.
   NB: This project was rejected by the Steering Group

Next Steps

Research design

Consistent with areas 1 & 2 above, the full range of questions suggested by survey respondents (including those subsequently rejected) will be analysed to find out whether there are any differences in suggested questions according to respondent characteristics. The following variables should be considered for collection as part of the survey:

- Respondent's role in relation to disease/condition – patient, carer, healthcare professional, part of organisation working for patients and/or other (may wish to distinguish between sub-categories of these)

- Respondent's age, gender and ethnic group

- Patient's age, gender and ethnic group (if not respondent)

- Patients: age at diagnosis, age at start of dialysis, time since diagnosis, time since start of dialysis

- Health care professionals: Number of years working with specific patient population, clinical specialty, clinical setting

- Some measure of respondent's education (e.g. highest qualification level)?

- Some measure of respondent's socioeconomic status (e.g. household income)?

Demographic questions should be asked at the end of the survey, with potentially sensitive questions last and with opportunities to opt out.

There should be a documented, transparent process for categorising suggested questions (including rejecting them), and the person/people categorising questions should be blinded to respondent characteristics during this process.

Once the data are collected, the following steps should be followed to clean and prepare the data for analysis (estimated time 20 hours, based on N=600 respondents and familiarity with SPSS):

1. Export data from SurveyMonkey into Excel, then from Excel into SPSS.

2. Explore data to check for errors/inconsistencies and missing data. Decide how to deal with any and document this process. Variables with >5% missing data could cause substantial bias and advice should be sought from a statistician regarding how to deal with these.

3. Create new variables for total number of suggested questions, total number of reframed questions, and number of reframed questions within each category.

4. Manually code each respondent according to the above variables. These data can be used (1) as a basis for deriving binary variables for analysis (see step 7) and (2) to report the range and median number of questions suggested per respondent, overall and within each category.

5. Delete any duplicate respondent entries, so that each respondent is only one unit of analysis.

6. Transform any other string variables into numeric variables (by numerically coding qualitative categories) – this can be done automatically in SPSS.

7. Derive new variables required for analysis (e.g. binary category variables (yes/no); 'patient only', 'carer only', 'HCP only', 'dual role') – this can be done automatically in SPSS.

Once data preparation is complete, the data can be analysed (estimated time 5 hours if familiar with SPSS):

1. Run univariable analyses of question category comparing (1) each role vs. everyone else (e.g. patient vs. not patient); (2) specific pairs (e.g. patient only vs. carer only, patient only vs. HCP only, etc.); (3) demographic characteristics.

Run multivariable analyses of question category, including variables found to be 'associated' with question category on univariable analysis (ideally $p<0.25$ to ensure inclusion of all potentially confounding factors, but $p<0.1$ is commonly used). Variables significant at the 5% level on multivariable analysis ($p<0.05$) would appear to be independently associated with the question category.

Potential outcomes

Similar research being undertaken with data in the Type 1 diabetes PSP is showing statistically significant differences between the type of questions chosen by patients, carers, and healthcare professionals, and also indicates that questions chosen by patients and carers are the most likely to be rejected as "not a treatment uncertainty".

While research of this type may be condition-specific up to a point, there is concept generalisability in the general outcome:

Firstly, if patients' and carers' priorities can be shown to differ significantly from those of healthcare professionals, it demonstrates the value of PPI in priority setting.

Secondly, if patients and carers are shown to differ significantly in terms of priorities and type of suggestions made, it has implications for the more usual approach in PPI where carers are seen as proxies for patients.

Finally, if the PSP process means that some groups' research questions are more likely to be rejected than others, this suggests a need for more work to look at how and why that happens, flagging this as an issue for all PSPs to consider (if time allowed, the Kidney PSP's second research suggestion would help inform this by opening the 'black box' of what happens to questions submitted by survey).

Appendix A: the PiiAF process

Figure 1: The Structure of the PiiAF Guidance

Part 1: Using the PiiAF to explore impacts and how they are shaped

Text Box 10

Values associated with public involvement in research

Practical issues shaping public involvement in research

Impacts of public involvement in research

Approaches to public involvement in research

Research focus and study design
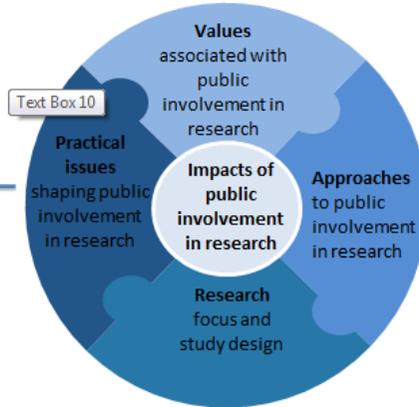
We present each of the 5 elements in turn in this Guidance. For each element we include sections on:

- Key issues for that topic
- Questions for discussion and debate
- A resource list

Recording key points from your discussion

Values	
Approaches to PI	
Research Focus and Study Design	
Practical Issues	
Identifying the Impacts of PI in Research	

A recording card is provided to capture points arising from discussion of each element in Part 1. This record card provides the building blocks for developing an impact assessment plan in Part 2

Part 2: Developing an impact assessment plan

Phase 1 Laying the Foundations

Phase 4 Forumulating assessment questions and study design

Developing an Impact Assessment Plan

Phase 2 Developing your intervention theory

Phase 3 Identifying possible effects of context on impacts of public Involvement

A series of resources are provided to support users of the guidance including:
Summaries of more information on a topic
Resources to stimulate discussion of issues raised in PiiAF.
In-depth information and reference lists
Searchable databases of previous impact studies and tools and techniques to assess impact

10

11

Appendix B: the JLA process

Initial enquiry
- via NETSCC
- check of readiness
- appoint advisor

Steering Group convened
- with JLA Chair
- sign off protocol

Initial awareness meeting
- optional

Identification of uncertainties
- collected from survey
- harvested from literature
(up to 2,000 uncertainties)

Sifting
Information Scientist sifts and removes duplicates
- peer review and input from Steering Group essential

Checking
Information Scientist checks literature to make sure uncertainties are true unknowns
- peer review and input from Steering Group essential

Presentation of uncertainties
Uncertainties combined or split as appropriate
- peer review and input from Steering Group essential
(up to 170 confirmed uncertainties)

Interim Priority Setting
Remote interim vote on long list by all interested parties

Analysis
- by Steering Group
- check balance of responses
- JLA challenges decisions
- creation of short list (20-30 uncertainties)

Identify Top 10
Final PSP meeting to rank the 20-30 uncertainties

Next Steps
Outcome from final PSP meeting = published Top 10 uncertainties
- format of data for all true uncertainties quality checked and then recorded on DUETs

Communication
- development of uncertainties into research questions by Steering Group
- dissemination to research programmes
- publish paper