Evaluation of the Type 1 Diabetes Priority Setting Partnership

Introduction

The James Lind Alliance (JLA) Type 1 Diabetes Priority Setting Partnership (PSP) was established in 2010. The PSP began its process in June 2009, with an initial awareness meeting for stakeholders, and held its final priority setting workshop in May 2011, where a top 10 list of type 1 diabetes treatment uncertainties for research, plus one overarching goal, were agreed by patients, carers and clinicians.

In order to understand participants' experiences of the JLA process, and gather their feedback, everyone involved with the PSP was asked complete an anonymous online survey. This included those who participated throughout the process as well as those who contributed to just one or two stages. The JLA will use this data to develop its methods and to continue to work effectively with future PSPs.

This report summarises the feedback. Forty two responses were received. Percentages may not add up to 100 due to rounding. While participation in the survey was anonymous, care has been taken to ensure the analysis does not reveal any individual identities.

The respondents

Of the 42 respondents: 71 per cent were patients, patient representatives or people with type 1 diabetes; 19 per cent were clinicians and 10 per cent were carers.

Information provision

The majority of respondents were satisfied with the level and detail of the information provided to them throughout the JLA process, with 37 per cent saying they were satisfied and 34 per cent saying they were very satisfied. Twenty two per cent were neither satisfied nor dissatisfied, while seven per cent (three people) were dissatisfied. While one person stated that they had not received enough information, comments were largely positive:

> *The staff that helped me was very informative on the procedures and helped me stay involved properly.*
>
> *The information I received enabled me to complete the survey and understand the rationale behind what I was being asked to do and why.*

> *I felt I was always kept up to date with what was going on, even when I did not bother responding! So thank you for the good customer service - keep it up.*
>
> *The information provided - and its level - was clear and comprehensive for me, from the beginning of the exercise when I/we received the explanation about what was planned, as well as supplementary documents which were attached. Also provided was the opportunity to enquire further about some of the arrangements.*

Some suggestions for further improvements were made:

- more detail early on about anticipated timetable
- the length of the process should be reduced – patients have a sense of urgency about their condition
- more detail on the background of the uncertainties for those who were not involved in the harvesting stage
- clarity in the final workshop invitation that places are limited, and thus not everyone will be able to attend

Meetings and communications

The majority of respondents (90 per cent) had not attended the introductory meeting. They gave a range of reasons, including ill health, work commitments, distance from location and not knowing about it.

Most respondents (61 per cent) were satisfied or very satisfied with the way the JLA communicated with them between meetings. Thirty four per cent were neither satisfied nor dissatisfied. One respondent was dissatisfied and one was very dissatisfied, but did not say why. Comments included:

> *Plenty of information and an ethos that invited responses and questions at any point.*
>
> *Information was clear and provided a good report of the meeting and next steps.*
>
> *It is always helpful to know what is going on, and to have some form of feedback about progress, planning, and so on.*

Submitting uncertainties

Sixty three per cent of respondents had submitted uncertainties. Those who had not submitted any gave explanations including lack of time, lack of inclination and that they had not been involved in the PSP at that stage.

Of the respondents who did submit uncertainties, 77 per cent were satisfied or very satisfied, while 23 per cent were neither satisfied nor dissatisfied with the process. No one was dissatisfied. Comments included:

> *Again the process was explained well with the right amount of information provided and the survey process was easy to use/follow.*

> *It allowed opportunities for free, open and honest communication, and also the feeling that 'something was being done'.*
>
> *Better than a lot of surveys.*

It was also suggested that the survey should not be open for so long, to make people respond more rapidly and to condense the overall process.

Interim priority setting

Fifty three per cent of respondents participated in the interim priority setting exercise, ranking their top ten treatment uncertainties from the long list. Those who had not taken part at this stage explained that they were not involved in the PSP at that time, or they had not been invited to participate.

Of those who did take part, 55 per cent were satisfied with the process and 20 per cent were very satisfied. Four people were neither satisfied nor dissatisfied. One person was dissatisfied. Comments and suggestions included:

> *[There were] clear instructions on what was need and time given to complete, giving you time to think about what is being asked of you and why you were making those choices.*
>
> *I was satisfied by the initial survey but felt the survey giving me the opportunity to select my top so many was biased into assuming there were issues in certain areas.*
>
> *I felt the way a number a number of uncertainties were worded was biased.*
>
> *To be truthful, although it was highly democratic, it was hard seeing my priorities being compromised to include other people's!*
>
> *I was satisfied that we were given the chance to prioritise what we felt are important to us, just unsatisfied with the limited number! There were an awful lot of important issues that we as patients desperately need answers to, which I commend you for looking into, but it also made it challenging to prioritise.*
>
> *It was informative to see such a list, which was quite comprehensive, and to be able to put that list into our own order of priority. Whilst reading through it, I found that some things hinged on others, some were of no interest to me personally, and some were of great importance to me. It really helped to read and be able to make choices between those interim priorities.*
>
> *Mostly happy with this, but one or two reservations: 1. some overlap between topics; 2. some which I felt we already knew the answers to (but perhaps haven't communicated well enough to patients).*

Final priority setting meeting

Fifty eight per cent of respondents attended the final priority setting meeting. Those who did not attend gave reasons including work commitments and not knowing about the meeting. Among those who attended, 73 per cent were very satisfied or satisfied, and 27 per cent were neither satisfied nor dissatisfied with the process. No one was dissatisfied. Comments included:

> *Realising that so much research and, as such, funding is needed to undertake the work to find a cure for Type 1 diabetes, it was of great benefit for all participants in the latter stage of the process at Friends' House to be able to see all the priorities there were on the sheets of paper and, ultimately, to be able to put them into an order with which most of us agreed.*
>
> *The organisation and management of the whole event seemed to go smoothly; it was apparent how much went into organising it. Many thanks for giving me the opportunity to participate. An extremely good opportunity to meet others involved and learn about different aspects of the JLA process.*
>
> *A very useful exercise which I found much more enjoyable than I expected. Good to engage with patients on an intellectual as distinct from a purely clinical/personal level.*
>
> *Very clear on the process being used. No time wasted and felt everyone had a chance to voice their opinion.*
>
> *Very friendly atmosphere and the whole day was very engaging and rewarding for those involved.*

Some concerns were expressed about the wording of the questions, with a perception that many were too similar to be considered separately, leading to a polarisation in the way different groups ranked questions they deemed similar, which led to confusion. It was suggested that not being allowed to alter the wording was too rigid a rule. For one participant, this was particularly frustrating, and it was suggested that rewording could be incorporated into the day for all participants to contribute to.

Finally, there were varied perceptions about the input of the different stakeholder groups. For example, one participant suggested that a patient agenda had dominated the proceedings. Another suggested that as a carer, they had not felt able to be open about raising issues which patients might find sensitive. Another participant felt that clinicians should not have a vote within the process, given their professional contacts, training and opportunities to influence the research agenda.

Overview of the JLA process

Sixty per cent of respondents said they thought the priority setting process was fair and in line with the JLA's objectives of independence and freedom from bias. A third were not sure and two disagreed. Concerns included perceptions of the legitimacy of clinicians' involvement and how the wording of the questions might be seen as biased. There were also differing views that there were both too many and too few patients involved in the final meeting.

> *I think the questionnaires were fine, however, the timing & location of the meeting discriminated against certain groups of people. Perhaps a second meeting in a different part of the country, on a different date and in the early eve./on a weekend, with outcomes pooled, would have been more representative.*

Other comments included:

> *As a Type 1 diabetic since [the 1970s], my goal is for a cure to be identified within my lifetime. As such, I am biased. However, at no stage did I feel that any bias was shown by the JLA. The whole procedure of the priority setting process seemed completely fair and in line with the JLA's objectives of independence and freedom from bias.*

The majority of respondents (55 per cent) felt that working with the JLA to prioritise treatment uncertainties for research will make a positive difference to patients, clinicians and researchers in the field of type 1 diabetes.

> *The more opportunities there are to pool and process information, and hear what other diabetics think, the better.*

> *Having the opportunity to work with the JLA can only make a positive difference to patients/clinicians/researchers in unison. The combined knowledge and experience of all 3 sectors makes a significant and very positive difference in furthering the work of the JLA.*

> *I have at least been able to say what I would like to see.*

Five per cent (two people) felt that the process would not have an impact, and a third were unsure.

> *It can only make the real difference if there is funding for the researchers to undertake the research.*

> *Our charity funds research according to its own research strategy. The JLA priorities are broadly in line with those of the charity, and are unlikely to influence the decision-making process.*

> *I am not yet convinced that this process will make a huge difference in terms of research agendas of large departments, or of grant-awarding bodies - remains to be seen. I hope it works - seems like a very good idea.*

> *I am not sure that the field of Type 1 diabetes is yet sufficiently open-minded to take on board the JLA philosophy […] Sadly I think the top few priorities selected will not particularly impress researchers or funders. They relate to industry development and are likely to happen anyway due to commercial interests. Undoubtedly they are important priorities for people with diabetes but it seemed more like a demand than a treatment uncertainty.*

Two thirds of respondents said they would recommend the JLA process to their colleagues or peers.

> *It was very open and inclusive; I felt it encouraged participants to think more openly about research.*
>
> *It is a great way to foster dialogue between patients, carers, clinicians and researchers.*
>
> *Thank you for the opportunity to provide input into these important areas and good luck with the research that comes from it.*

Just over a quarter (26 per cent) were unsure, and three people said they would not recommend it.

> *I'd certainly recommend that they find out more and adopt some of the basic principles, but I'm not sure yet whether I'd recommend it without reservation.*
>
> *Cumbersome and not certain that it is valuable.*
>
> *The staff were professional and helpful - and led well. The main problem lay in the final choice and the wording of the questions.*

Aspects of the JLA process which respondents felt worked particularly well were:
- the survey
- the inclusion of patients, carers and clinicians
- the attitude of the participants
- the opportunity to engage in discussion with a range of peers
- a good balance of different interests
- the staff and their organisation of the process
- the transparency of the process

Aspects which participants would like to have changed were:
- to have had better worded questions with less overlap between them
- to have had more meetings at different times and in different locations to enable a wider range of people at attend
- to have had more input from clinicians
- to have had a better balance in the number of patients, carers and clinicians at the final workshop

Recommendations for the JLA

- Ensure people are aware of a rough timetable for stages and completion, with an indication that they are subject to change.
- If the process needs to be lengthy (ie more than one year), ensure all partners are kept informed as to why this is necessary (eg keeping the survey open for a long period in order to reach all stakeholder groups).

- At interim and final priority setting stages, make clear where the uncertainties have come from - some participants will not have been involved in the harvesting of uncertainties, and should be made aware of the wide and inclusive range of stakeholders involved in identifying them.
- In order to eliminate perceptions of bias, ensure participants are clear how the interim short list has been compiled, if it has been reduced from the long list by the Steering Group.
- It is imperative that the Steering Group checks and formally signs off the wording for both the interim uncertainties and the final short list, including stating their confidence that there are no duplicates or uncertainties which would be better combined. Consider consulting with a small group of external experts to gain a fresh perspective on the data.
- In inviting participants to the final meeting, make clear that an equal number of patients, carers and clinicians are required, and that attendance is therefore not guaranteed.
- Explain in advance why a top 10 list is sought (and that the others will not be lost), as some people will find it challenging to reduce their uncertainties to this small number.
- Agree a process for dealing with requests for rewording or combining uncertainties. While the risk should have been minimised prior to the final meeting, where requests are made, a consistent response needs to be applied (even if that means allowing the full group to decide).
- Make clear at the final meeting why the JLA seeks input from patients, carers and clinicians, and emphasise their equal value to the process.
- Consider prior to the final meeting whether carers face any particular barriers to participation, and ensure they are represented in equal numbers to patients and clinicians respectively.
- Consider holding meetings at weekends to allow people who work to attend. Encourage partner organisations to consult locally with their stakeholders, to ensure their input even if they cannot attend meetings in person.

Written by Katherine Cowan, James Lind Alliance, August 2011