

*A summary report of preliminary focus
group consultations with service users
at Great Ormond Street Hospital, held
on 29th August 2012*

Patient Reported Outcome and Experience Measures (PROMs and PREMs): Service Users' Perspectives

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Introduction

There is an increased emphasis in the NHS on development and application of Patient Reported Outcome and Experience Measures (PROMs and PREMs) as a means of patient-led assessment of health outcomes and care.¹ Equally, in keeping with the ethos of Great Ormond Street Hospital (GOSH), it is essential that these measures are developed and applied with the involvement of patients and their families.

To address the current strategies and challenges concerning development and application of PROMs and PREMs for children and young people, we set out to organise a multi-professional workshop on 3rd October 2012 for academic and clinical colleagues from UCL Institute of Child Health and its two key clinical partners GOSH and Moorfields Eye Hospital (MEH). To inform the workshop, as a first step to exploring patient and parent views of PROMs and PREMs, we undertook expert service user consultations with a small group of patients attending GOSH services and their family members. These were held in form of two focus groups, one with young people who are currently, or have been, patients of GOSH, the other with their parents or carers and wider family members. The objective of these discussions was to capture, in the first instance GOSH service users' views on PROMs and PREMs to understand how to engage effectively with patients and their parents so they understand the importance of completing these questionnaires as part of routine clinical care. Following the focus group discussions, two parents who were focus group participants were invited to participate in the workshop and contribute their perspectives along healthcare professionals.

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This report highlights the key findings from these focus groups.

Methods

Two separate focus groups were held in parallel, one with patients and one with accompanying family member/parent(s). The participants were 6 patients (3 aged 10 years

¹ Patient-Reported Outcome Measures (PROMs) are self-report questionnaires designed specifically to measure the impact of illness/health condition (e.g. quality of life, symptom severity, functional status, health status etc) from the patient's perspective. They can be helpful in monitoring the progress of a health condition or whether a treatment has been effective, by looking at changes in the questionnaire scores. Patient Reported Outcome Measures (PREMs) are questionnaires designed specifically to assess the patient's view of what happened during health care (e.g. waiting time at the hospital; duration of appointment). They can be used to evaluate quality of health care and monitor improvement in services. Whilst PROMs are concerned with *the outcomes* of health condition or disability, PREMs are concerned with the *process* of healthcare.

and 3 aged 16 years, 5 female and 1 male) attending different GOSH services and 12 family members (11 parents and 1 grandparent², 9 female and 3 male).

The child focus group was facilitated by Rehana Ahmed, Patient and Public Involvement and Experience Officer, Anna Gregorowski, Nurse Consultant and Lisa Davies, Clinical Outcomes Lead³ from GOSH. The parent focus group was facilitated by Val Tadić, research associate, and Ailbhe Hogan, research assistant, from MRC Centre of Epidemiology of Child Health at UCL Institute of Child Health.

A semi-structured focus group topic guide was used to explore the initial reaction to of PROMs and PREMs used at GOSH, user experience of completing PROMs and PREMs, understanding of the purpose of these measures, preferences for administration, issues with answering sensitive questions potentially covered by PROMs and PREMs and suggestions and ideas for improvement to the process of use of PROMs and PREMs.

For the patient group, flexibility was applied to topic guide to enable interactive age-appropriate group-work (e.g. Ice Breaker – human bingo and Judgement exercise – to encourage the group to qualify and quantify their responses during the session).

Findings

From the qualitative data transcripts the findings were derived thematically, bringing together the related issues raised by the parents and children and young people (i.e. patients) as follows:

1) Importance of communication and information provision

Parents

- There is a general feeling of a lack of communication, from the service providers, regarding the purpose of the questionnaires and one of the initial reactions to being given PROMs and PREMs was to ask: what is it being used for and where is this information going?
- Parents would be more likely to fill in a questionnaire if they knew precisely why their response was necessary and beneficial to their child or the hospital (i.e. a motivational factor).
- The parents emphasised the need for feedback after filling in a questionnaire. Without any feedback parents are left believing that the information they are providing is not being used to serve any purpose by ‘going into a black hole somewhere’ or that their opinion is being ignored. Lack of information and feedback can reinforce negative connotations with regards to questionnaire data gathering (e.g. government driven agenda).

² We have taken on board all the participants’ views in writing of the report, although, for brevity, we refer to family members as parents in the remainder of the report.

³ Lisa Davies has since left GOSH.

- Some parents had positive experience with completing PROMs i.e. in cases where the questionnaire was overtly used by the clinician to monitor progress and fostered parental understanding of their role as markers of progress or symptom monitoring.

Children and young people

- Patients wish to be told that the information they give has value and will serve a purpose. They felt that information was lacking about why they needed to complete questionnaires and because of this, they did not see the point of completing them.
- Patients would be more inclined to fill in surveys if it helped them directly, although there was a desire to help others too, for example new patients or to help patients decide if they want a particular treatment.
- Patients showed understanding that questionnaires were used to see what progress was being made, both by the patient and the clinician providing the care.
- There is an expectation by the patient group for staff to talk to them about their answers.

2) Questionnaires as an information gathering method

Parents

- Parent see questionnaires as a method of information gathering as impersonal and user-unfriendly. Many questionnaires seem long, daunting and overwhelming, while shorter, clear and simple questionnaires generally received more positive reactions.
- Some parents feel that the language in questionnaires lacks sensitivity, making the questionnaires appear sterile and clinical.
- There is a feeling that the lack of flexibility within the questionnaires over-simplifies the child's illness.
- Whilst some parents feel that suggestive negative language in some of the questionnaires can be very off-putting e.g. 'trouble' (e.g. this may produce negative connotations and encourages the responder to concentrate on their child's difficulties), for others this type of language is helpful as it is indicative of understanding and recognition of the type of difficulties the family experiences
- Acronyms (e.g. FDI, PedsQL) and footnotes, whilst helpful to professionals, are not meaningful to the parent or child and can be a distraction.

Children and young people

- Like parents, patients prefer for questionnaires to be short and simple. However, their concern is that questionnaires are often not specific enough, so they acknowledged the need for longer questionnaires in order to ask about related issues in more detail.
- Patients prefer the booklet style questionnaire format as it makes the questionnaire feel shorter.
- The younger patients have a perception that there are right and wrong answers when completing questionnaires and would not feel entirely confident completing the questionnaires by themselves. They would want an adult present (whether a parent or a nurse) to explain difficult words or to check back their answers. Not knowing how to respond would stop them completing a questionnaire.

- The older group are less concerned with whether there are right or wrong answers. They are more concerned that their response does not always fit a particular box or pre-specified response. They value the inclusion of an 'I'm not really sure' or 'I don't know' response option as this would enable them to answer the questionnaire more accurately. Sometimes the true response is between two given options and the group said they would tick in between the options that were most relevant to them.

3) Considerations for questionnaire completion in routine practice.

Parents

- Failure to provide adequate information and feedback about the purpose of PROMs and PREMs can have important implications on the respondent's motivation to complete the questionnaires or their trust in services, e.g., not understanding the purpose and lack of feedback can lead to the belief that their contribution is being ignored.
- The parents raised the issue of the fear of repercussions i.e. that if they answer honestly and give negative feedback this could somehow impact negatively on their child's healthcare.
- Some parents may be afraid of being judged as a bad parent if they were honest when filling in the questionnaires, especially when it comes to personal questions and highlighting negative outcomes.
- Parents are worried that their children (teenagers in particular) do not always want to answer honestly. This is because they may be afraid of having to go through more difficult treatment regimens or they do not want to cause trouble and 'rock the boat', without having an understanding of why it is important to be honest.

Children and young people

- Patients felt strongly that their time is precious too and they did not want to waste it by completing questionnaires they feel nobody is going to use or respond to.
- Privacy and confidentiality issues were emphasised. The older patients would not answer particular questions if there was a chance their parents would become aware of their responses (e.g. issues surrounding smoking and alcohol consumption). They also felt that questions about emotional well-being are too sensitive to share with parents. The group consensus was that they had no problems answering questions relating to physical health in front of their parents but those about mental health and emotional wellbeing would not be answered at all or would not be answered truthfully. They want to be explicitly asked whether the information they give on the questionnaires could be shared with other people, including their parents. The older patients said that as 16 year olds, their consent/permission should be sought all the time but felt that if the patient was a bit younger, or if the subject matter was not too sensitive, a little flexibility could be applied.
- Motivational factors were emphasised: Patients would be motivated to complete the questionnaire by presence of images/pictures/smiley faces and other visual aids on them, particularly if the questionnaires were simple and not time consuming. Younger patients are keen on incentives and rewards. Being asked to complete questionnaires repeatedly is a turn off. Unless it was clear how the questionnaire is relevant, to them or other people, they would not complete it.

4) Considerations regarding child vs. parent reporting.

Parents

- Parents emphasised the value of both parent and child report to get both perspectives on illness. Parents have a concern that their children may not always be able to present an accurate assessment of their illness because they may not fully grasp the seriousness of it and sometimes provide answers that do not reflect the true reality of how they are affected. This is a concern for parents because of the implications of child downplaying their illness could have in terms of health care provision.
- Parents highlighted the positive aspects of child self-report questionnaires, in that they may facilitate communication by allowing the respondent to answer sensitive questions that they may not feel comfortable verbalising. They may also facilitate direct communication between the clinician and the child, as many young people do not feel comfortable talking to their parents about all that is bothering them, or recognise the importance of communicating these issues to their parents.
- Parents raised the issue of the aftermath of questionnaire completion, if sensitive information is revealed. They were concerned about the consequences of breaching the child confidentiality if the parent or clinicians revealed to one another a specific sensitive issue about the child.

Children and young people

- Patients have a need to report on their experience and views, and emphasised the importance of privacy and confidentiality.
- The patient group was asked to rate the importance of parental involvement/presence when they completed the questionnaire. For younger patients, it was of high to medium importance and for older patients of low importance.

5) Preferences for method and context of PROM and PREM completion.

Parents

- Parents prefer postal administration of PROMs or PREMs over completion during the hospital visit because: it feels more personal, it allows more time to think about responses, without feeling rushed, it is less stressful (i.e. appointments are generally anxiety provoking and may not be a good time to elicit accurate self-reported information, even during the waiting times) and allows consultation with other family members who might not ordinarily get the opportunity to fill in these questionnaires.
- Online completion of questionnaires prior to appointments was highlighted as an easy and convenient option, and particularly attractive to teenagers (as an alternative to postal administration).

Children and young people

- Patients prefer paper questionnaires because they are easier to use and not everyone knows how to use the technology (e.g. iPad). Paper questionnaires allow

the child to think about what to write, allows for additional comments and recording answers that fall between the 'yes' and 'no' categories.

- If having to do them at hospital they would prefer to complete the questionnaires while waiting for their appointment at the hospital and not after their appointment because they just want to go home.

6) Recommendations for routine use of PROMs and PREMs.

Parents

- A simple introductory paragraph explaining the purpose, in terms of what the PROM or PREM measures and what it will be used for.
- A website address where patients fill in the questionnaire and receive feedback.
- Further emphasis on user-centred approach to improving existing and developing new questionnaires e.g. inclusion of both children and parents when developing PROMs and PREMs, particularly in relation to the improvement of aesthetics (e.g. presentation and layout) and language (e.g. child-friendly and sensitive).
- For questionnaires used at GOSH, GOSH branding would have value, e.g. hospital logo, as it would increase the understanding that they form part of GOSH service and would reassure the patients what they are for.
- A set of guidelines for GOSH regarding these questionnaires (e.g. development, purpose and outcomes), which can be shared with service users. This would ensure that all measures reflect the aims and priorities of the hospital and that their purpose is clear to service users.
- It would be useful to have appropriate staff available to help children (particularly those unable to self-report) to fill in the questionnaires, so that they can offer their views independent of their parent.

Children and young people

- Important to have an explanation of relevance of completing the questionnaire
- Patients want colourful surveys, images and visually attractive booklets. They also require clarity of language and specific questions.
- For younger patients, it is important that an adult is on hand to help out if they get stuck with a question as they perceive that there are wrong and right answers and would feel anxious at the thought of getting a question wrong. Nurses are viewed as suitable adults to help out.
- Token rewards for completing questionnaires are welcome and suggested rewards were lollipops, stickers, pens, badges.

Summary

This reports summarises a first exploration of patient and parent perspective of using PROMs and PREMs as part of routine clinical care at GOSH, based on focus groups with a small group of GOSH patients and their parents. With regards to PROMs, the focus group participants had mainly experience of PROMs as a tool for monitoring individual patient's care. The report highlights some key issues important to patients and their families

attending GOSH with regards to completing PROMs and PREMs: the need for adequate information provision to allow them to understand the purpose of PROMs and PREMs they are asked to complete; the importance of receiving feedback following their completion in terms of how this information contributes to their child's individual care or the health service in general; patient and parent preferences for the completion of questionnaires in routine clinical practice; and the issues, such as confidentiality and differences in perspective, related to obtaining parental and child patient report.

We recognise that these findings are based on a discussion with a small group of parents and children and young people attending specific GOSH services and the views expressed are not fully representative of the GOSH service user population. This bias may have also been reflected in positive experiences being reported specifically by a group of parents attending a specific GOSH service who have had an experience of a specific questionnaire. Additionally, we did not pilot the topic guide on a smaller group of parents and children, which would allow a clearer focus on particular topics of interest. For instance, we used a number of questionnaires as examples, with both PROMs and PREMs to demonstrate the variety, which may have diluted a focus on specific issues. Examples of PROMs were not prepared specifically for the focus group (e.g. distracting information was not removed), which may have contributed to negative initial reactions from the participants.

Nevertheless, these discussions were an invaluable first step to understanding a patient and family perspective of PROMs and PREMs, which was an essential component of our recent multiprofessional workshop. We hope to run future expert user consultations that will focus on evaluating service user perspectives relating to specific PROMs or PREMs and their use and effectiveness with specific health conditions and specific hospital services. We will also aim to capture the experience and perspectives of families from different cultural and socio-economic backgrounds. This will involve further development and implementation of innovative and flexible PPI strategies for development and implementation of valid, reliable and user-friendly PROMs and PREMs in routine clinical care. This approach is critical to ensuring that clinical practice and health policy relating to PROMs and PREMs can truly be shaped by what matters most to our patients.

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